

Negotiating healthcare through partnership: An exploration of the perceived and observed factors that enable or inhibit partnership between young “expert” patients with Cystic Fibrosis and the Healthcare Professionals with whom they interact.

Kath MacDonald

Submitted in partial fulfilment for the award of Professional  
Doctorate in Health and Social Sciences

6<sup>th</sup> January 2014

Queen Margaret University, Edinburgh

## **Declaration**

**I declare that this is my own work**

**The stated word count is 49, 359 excluding appendices and tables**

**Signed** ...*Kath MacDonald*.....

**Date**.....6<sup>th</sup> January 2014.....

## **Acknowledgements**

Thanks are accorded to several groups of people without whom this thesis would not have been possible.

Firstly to the young people and healthcare professionals who participated in the study and gave of their time and experience. Secondly to my Director of Studies Dr Shona Cameron for her enthusiasm, sound advice and constant support throughout my doctoral studies. To my supervisors Dr Margaret Smith and Dr Lindesay Irvine, thank you for the support and guidance offered during the writing of the thesis.

To Philip, Bill, Kevin and Janice; many thanks for the editorial work.

Thanks must also go to my colleagues at QMU, who supported my study leave and helped me manage the workload of combining a full-time academic role with doctoral studies. I hope I can return the favour.

Finally, thank you to family and friends for emotional and practical support over the past six years.

## **Abstract**

Since the late eighties healthcare policy has seen a shift from a paternalistic model of care to that of an inclusive partnership approach which encourages engagement, responsibility and self-management of long term conditions. This paradigm shift has given credence to the notion of the “expert patient” (EP); an individual with a long-term condition whose knowledge and skills are valued and utilised in partnership with healthcare professionals. However, there is debate as to the definition of the EP, and an assumption that all patients would want to adopt this role and a partnership model of care. There is also scepticism about the motivation behind the introduction of the EP and the perceived benefits of EP Programmes.

This study aimed to explore how young “expert patients” living with cystic fibrosis (CF) and the healthcare professionals (HCPs) with whom they interact perceive partnership and negotiate care.

Adopting a qualitative methodological strategy, informed by Interpretivism and Symbolic Interactionism, thirty three consultations were observed between eight patients, two accompanied by a carer and twelve healthcare professionals (HCPs). Following the observed sessions the eight patients, two carers and eleven HCPs were interviewed.

Data were analysed thematically using the five stages of “Framework” a matrix-based analysis approach. Three major themes emerged from the data: experiences of partnership, attributes of the expert patient and constructions of illness. Multiple sub themes are also presented, including the power of the nurses, normalcy, the expert patient as navigator and the ceremonial order of the clinic.

Implications for practice suggest the need for ground rules outlining both parties’ roles and responsibilities in partnership, a remodelling of the clinic format to ensure patient-centredness and a consideration of the role of decision tools and Telehealth in any new proposed model.

<b>CONTENTS</b>	<b>Page</b>
Acknowledgements .....	2
Abstract .....	3
List of Contents .....	4
List of Tables .....	9
List of Figures .....	10
List of Appendices .....	11
Outline of the thesis .....	12
 <b>CHAPTER ONE: INTRODUCTION .....</b>	 <b>13</b>
1.0 Introduction .....	13
1.1 Rationale for the topic: Personal and professional .....	15
1.2 Defining terms: chronic illness .....	16
1.3 Summary .....	17
 <b>CHAPTER TWO: METHODOLOGY FOR THE LITERATURE REVIEW .....</b>	 <b>18</b>
2.0 Introduction .....	18
2.1 Search Strategy .....	20
2.2 Cystic Fibrosis and its management .....	24
2.3 Constructions of Chronic Illness and Normalcy .....	25
2.4 Constructions of Illness and Self-Management .....	28
2.5 The Expert Patient .....	29
2.6 The Young Expert Patient .....	31
2.7 Summary .....	33
 <b>CHAPTER THREE: PARTNERSHIP .....</b>	 <b>34</b>
3.0 Introduction .....	34
3.1 Defining Partnership .....	34
3.2 Attributes of Partnership .....	35
3.3 Perceptions of Partnership: HCPs .....	36
3.4 Perceptions of Partnership: Patients and Families .....	39
3.5 Summary .....	41

	<b>Page</b>
<b>CHAPTER FOUR: SOCIAL INTERACTIONS BETWEEN PATIENTS AND HEALTHCARE PROFESSIONALS IN THE CONSULTATION .....</b>	<b>42</b>
4.0 Introduction .....	42
4.1 Asymmetry in the Consultation .....	42
4.2 Decision-making in the Consultation .....	46
4.3 Consultation Settings .....	47
4.4 Use of Cues in the Interaction .....	48
4.5 Summary .....	52
4.6 Summary of the Literature Review .....	53
 <b>CHAPTER FIVE: METHODS .....</b>	 <b>58</b>
5.0 Introduction .....	58
5.1 Researcher Perspectives on “Knowing” and “Being”: (Epistemology and Ontology) .....	58
5.2 Exploration of Beliefs .....	57
5.3 Making Sense of Theoretical Frameworks .....	58
5.4 Theoretical Perspective .....	62
5.5 Critique of Symbolic Interactionism.....	64
Methodology: Descriptive Interpretivism.....	64
5.7 Summary .....	66
5.8 Methods .....	66
5.9 Design .....	67
5.10 Observation .....	67
5.11 Structured/Non-Structured Observations .....	68
5.12 Interviews .....	70
5.13 Pilot Study .....	71
5.14 Sample .....	72
5.15 Recruitment .....	75

	<b>Page</b>
5.16 Tools.....	77
5.17 Data Analysis .....	78
5.18 Computer-Assisted Software in Data Analysis .....	79
5.19 Thematic Analysis Framework .....	79
5.20 Trustworthiness and Authenticity of Data .....	82
5.21 Field Notes .....	83
5.22 Respondent Validation .....	84
5.23 Peer Review .....	84
5.24 Reflexivity .....	84
5.25 Ethics .....	85
5.26 The Vulnerable Researcher .....	87
5.27 Access .....	88
5.28 Summary .....	89
 <b>CHAPTER SIX: RESULTS .....</b>	 <b>90</b>
6.0 Introduction .....	90
6.1 Contextualising the Clinic (Field Notes) .....	91
6.2 Researcher's Role .....	93
6.3 Non-Participant Observation:Reflections .....	94
6.4 Interviews .....	95
6.5 Results .....	95
6.6 Analysis of the Consultation Process using the Calgary-Cambridge Guide ....	.99
6.7 Analysis of Qualitative Data .....	101
6.8 Credibility and Trustworthiness of the Data .....	102
6.9 Peer Review .....	102
6.10 Respondent Validation .....	102
6.11 Reflexivity .....	102
6.12 Thematic Results .....	103
6.13 Defining Partnership .....	105

	<b>Page</b>
6.14 Power .....	106
6.15 Attributes of Partnership .....	107
6.16 Respect: .....	107
6.17 Negotiation .....	108
6.18 HCPs as Too Soft .....	109
6.19 Relationship-Building .....	110
6.20 Building Bridges to Achieve Adherence to Treatment .....	110
6.21 Competing Priorities/Agendas .....	111
6.22 Enablers of Partnership: Relationships between HCPs and Expert Patients; The Power of the Nurses .....	113
6.23 Acceptance of Experiential Knowledge .....	114
6.24 Barriers to Partnership .....	115
6.25 Systems and processes .....	115
6.26 Impact of life event/stage .....	116
6.27 Parental Surveillance .....	116
6.28 Lack of Trust .....	117
6.29 Relationships between HCPs and Expert Patients .....	119
6.30 The Expert Patient .....	119
6.31 Knowledge .....	120
6.32 Engagement .....	121
6.33 Emotion Work .....	121
6.34 Constructions of Illness: Embeddedness and Normalcy .....	123
6.35 Summary .....	124
 <b>CHAPTER SEVEN: DISCUSSION .....</b>	 <b>126</b>
7.0 Introduction .....	126
7.1 Limitations of the Study .....	126
7.2 Discussion: Experiences of Partnership .....	129
7.3 Outcomes of Partnership .....	138



	<b>Page</b>
7.4 Barriers and enablers to Partnership .....	145
7.4.1 Organisational Barriers .....	145
7.4.2 Attitudinal Barriers .....	148
7.4.2.1 Lack of Trust .....	149
7.4.2.2 Relationships .....	151
7.4.2.3 Not Being Listened to .....	152
7.4.2.4 Competing Agendas and Priorities .....	152
7.5 Enablers to Partnership.....	153
7.5.1 Relationships: The Power of the Nurses.....	153
7.5.2 Mutual Respect .....	157
7.6 How do Expert Patients Negotiate Care? Defining Expert Patients and their Practices .....	158
7.7 The Expert Patient as Navigator .....	160
7.8 Summary: Putting it all Together .....	163
 <b>CHAPTER EIGHT: CONCLUSION.....</b>	 <b>165</b>
8.0 Introduction.....	165
8.1 Comparison of findings to Hook's partnership model.....	165
8.2 Conceptual model of partnership.....	167
8.3 New knowledge.....	169
8.4 Implications for Practice .....	173
8.5 Dissemination .....	173
8.6 Future Research .....	173
8.7 Reflection on Personal Learning .....	174
8.8 Conclusion .....	175
 <b>List of References .....</b>	 <b>177-2108</b>

<b>List of Tables</b>	<b>Page</b>
Table 1      Breaking down the research question using the PEO framework .....	19
Table 2      Key search terms and authors in search strategy .....	21
Table 3      Attributes of physician/patient expertise .....	29
Table 4      Attributes of partnership .....	36
Table 5      Research framework for the study .....	60
Table 6      Inclusion and exclusion criteria .....	74
Table 7      Example of recruitment strategy .....	77
Table 8      Stages of the Framework process .....	80
Table 9      Observed consultations .....	96
Table 10     Average consultation time per HCP .....	97
Table 11     Details of study participants .....	98
Table 12     Results presented in the narrative.....	104
Table 13     Analytical and <i>A Priori</i> themes .....	291
Table 14     Emergent and analytical themes .....	292.
Table 15     Revised partnership model .....	165
Table 16     New knowledge emerging through the research thesis .....	169

<b>List of Figures</b>	<b>Page</b>
Figure 1 Proposed Conceptual Model of Partnership .....	168
Figure 2 Final mind map: Partnership between EPs and HCPs .....	250
Figure 3 Early mind map: Partnership .....	290

<b>List of Appendices</b>	<b>Page</b>
Appendix 1 Definition and critique of common terms used in the thesis .....	209
Appendix 2 CASP Appraisal tool .....	212
Appendix 3 Calgary-Cambridge guide .....	213
Appendix 4 Topic guide for interviews .....	214
Appendix 5 Recruitment poster for potential participants .....	215
Appendix 6 Letter of invitation: patients .....	217
Appendix 7 Consent form: patients .....	220
Appendix 8 HCP Letter of invitation .....	222
Appendix 9 Gantt chart .....	225
Appendix 10 Transcript with descriptor .....	226
Appendix 11 Coding Index from Nvivo .....	230
Appendix 12 Tagged data .....	231
Appendix 13 Thematic chart .....	243
Appendix 14 Mind map: Partnership between EPs and HCPs .....	250
Appendix 15 Draft ethics application .....	251
Appendix 16 Letter of approval for study .....	285
Appendix 17 E-mail verification from peer reviewers .....	288
Appendix 18 E-mail verification from participant .....	289
Appendix 19 Early mind map: Partnership .....	290
Appendix 20 Analytical and A Priori Themes.....	291
Appendix 21 Emergent and Analytical themes.....	292

## **Outline of the thesis**

The thesis comprises eight chapters.

Chapter one comprises the introduction to and rationale for the study and gives definitions for the commonly used concepts within the study.

Chapter two begins with the methodology for the literature review and proceeds with an overview of cystic fibrosis. This is followed by a review of chronic illness and its construction and concludes with an examination of the literature on the expert patient. Chapter three explores the literature around the models, attributes, perceptions and outcomes of partnership.

Chapter four appraises the literature in relation to social interactions between patients and healthcare professionals; particularly the themes of asymmetry and the ritualisation of the encounter.

Chapter five explores the proposed theoretical framework, design and methodology for the study.

Chapter six reports the findings of the study presented thematically through the observational and interview data and field notes. Reflections on the role of the researcher are also presented in this chapter.

Chapter seven presents a discussion and analysis of the findings and the limitations of the study.

The final chapter highlights the new knowledge gained through the research process in the form of a conceptual model and revisits the research questions through Hook's model of partnership. Researcher reflections are also presented here in terms of the learning achieved through the doctoral process, and the implications for practice.

Agaogi (2013, p2) contends that there is much debate about the absence of "me" in scholarly writing, and suggests that passive sentences written in the third person risk "stripping away the spice from the dish" in PhD writing. Thus, where I feel it is imperative that my voice is heard I make no apologies for writing in the first person.

## **CHAPTER ONE: INTRODUCTION**

### **1.0 Introduction**

Since the late eighties healthcare policy has seen a shift from a paternalistic model of care (Friedson 1984, Creer and Holroyd 2006) to that of an inclusive approach which encourages engagement, responsibility and self-management of long term conditions (Lorig et al. 1999, McQueen 2000, Rogers 2009, Rogers et al. 2011). Several drivers are thought to have contributed to this shift including: demographic, epidemiological and moral transitions (Taylor and Bury 2007).

The increasingly ageing population and rise in the prevalence and reporting of long term conditions (LTC), (WHO 2008) within Scotland has resulted in two million people (40% of its population), living with a long term condition (Scottish Government 2012 b). Further, policy has seen a move away from acute services in hospitals to an anticipatory approach to care with increased provision of care in the community (DoH 2006, Scottish Executive 2007, Scottish Government 2010a,b), 2011, 2012a).

Additionally a policy focusing on self-management has been instigated with the intention of making more effective use of available resources in order to manage the growing rise in LTCs. (DoH 2004, Darzi 2008, Scottish Government 2012b). Currently England spends 70% of its health budget on management of LTCs (DH 2013).

A further motivation for self-management has been the Government's drive to increase patients' engagement in involvement and responsibility for their own health, particularly in the context of LTCs (Wanless 2004). Other factors influencing change were those of poor collaborative practice and systems failures highlighted in the media through cases such as Shipman (2002), the Bristol Royal infirmary Enquiry (2001), Allitt, Alder Hey

and the Mid Staffordshire Enquiries (Goodman and Clemow 2008, Francis 2013). These practices gave rise to claims of protectionism, paternalism, lack of transparency and breach of moral principles resulting in a lack of trust in services and a resultant rise in a consumer culture in healthcare (Sang 2004, 2009). There is also an acknowledgement by health professionals and policy makers of the autonomy of patients and the value of lay knowledge (Coulter 2002, Coulter and Collins 2011, Entwistle 2000, 2002, 2004, 2006a,b), 2010a,b), Entwistle et al. 2004, 2006, 2008a,b), 2010). Finally a revisioning of "patienthood"; from the definition of the patient as a passive object of medical attention, to one whose subjective experience of illness is relevant, active and transformational to the activities of health professionals (May 1995, 2006), has influenced this sea-change.

Thus twenty-first century healthcare aspires to present an ideology of patient-centred care operating in partnership with health professionals, with an emphasis on empowerment of patients and "a mutual NHS" (DoH 2000, 2005a,b), 2006, DH 2010, 2013, SE 2007, LTCAS 2008, NES 2009, LTCC 2010, SG 2010a,b), 2012a,b). The desire for this partnership and participatory approach is well documented in the nursing, medical and sociological literature as evidenced by the abundance of published research in this area, (Charles et al 1997, 1999, 2000, Holman and Lorig 2000, Barry et al. 2000, Coulter 2002, 2012a,b), Coulter and Collins 2011, Coulter et al. 2012, Wilson 2001, Wilson 2005, Henderson 2003, Daiski 2004, Bidmead and Cowley 2005, Brown et al. 2006, Lee 2007, McIntosh and Runciman 2008, Coyne 2006, 2008, Sang 2009, Wilson 2009, Greenhalgh 2009, Mikesall 2013). However, whilst many of these papers are small-scale exploratory descriptive studies, or position papers, they draw similar conclusions about the perceived lack of equality in partnership by patients and carers, (Rutter et al. 2004), despite the intent expressed in policy documents. This inequality has also been evidenced through observation of the social interactions between patients and healthcare professionals throughout the last six decades (Parsons 1951, Goffman 1959, 1971, Stimson and Webb 1975, Strong (1979), Tuckett et al. 1985, Waitzkin 1991, Lewin et al. 2001, Bensing and Verhaak 2004, Silverman et al. 2005, Heritage and Maynard 2006, Pilnick and Dingwall 2011, Fischer and Ereaut 2012).

The spirit of increased engagement and recognition of the value of the patient experience in the management of health has given credence to the notion of the “expert patient”, (DoH 2001); an individual with a LTC whose knowledge and skills are valued and utilised in partnership with healthcare professionals for their own self-management and that of others (DoH 2001). However, there is debate as to the definition of the expert patient, (Tyreman 2005a,b), Badcott 2005, Taylor and Bury 2007), the assumption that all patients would want to adopt this role (Wilson 2007), the motivation behind its introduction, (Wilson 2001) and the perceived outcomes of Expert Patient Programmes (Kennedy et al. 2005, Foster et al. 2007, Taylor and Bury 2007, Rogers et al. 2008, Coster and Norman 2009, Greenhalgh 2009, Savage et al. 2011).

### **1.1 Rationale for the topic: Personal and professional**

The aim of this study was to explore how young expert patients living with chronic illness and the healthcare professionals (HCPs) with whom they interact perceive partnership and negotiate care. The rationale for the study is driven by several factors. Firstly, as discussed above, there is an increasing focus on mutuality and partnership in healthcare between professionals and patients/clients/consumers which was perceived as worthy of further exploration. However, the topic of interest was also driven by my experiences of working as a nurse specialist with young people with chronic illness. During this period it was acknowledged anecdotally, experientially and through the literature that these patients displayed experiential and technical knowledge of self, disease and its management which might be perceived as expertise. In light of the recent attention on the concept of the “expert patient” in policy and in the nursing and sociological literature I felt that this area of “expertise” warranted further investigation. Further, in relation to my clinical career, the duration of chronic illness within this particular group of patients resulted in the establishment of long-term relationships between those who experienced the illness and those of us (HCPs) who were involved in its management. These relationships may or may not be perceived to be



partnerships, but aroused my curiosity to know more about how these relationship are viewed by each of the parties. A search of the literature provoked this curiosity further as it appeared that the language of partnership in policy was not always evidenced through the empirical research. Thus the two topics of interest: “expertise” and “partnership” were combined to form the research question.

## **1.2 Defining terms: chronic illness**

There has been a degree of confusion regarding the terminology in the field of chronic illness with earlier definitions derived from a biomedical stance making reference to disease and dependency (Wilson 2007). Historically the imagery associated with chronic disease has implied disability and incapacity and was largely negative, (Wilson 2001, Walker 2001). Wellard (1998) contends that umbrella terms such as “chronic conditions” have been adopted in an attempt at inclusiveness. This can be seen through the change in language in recent policy documents which cite “long- term” or “enduring conditions” (DH 2013, Scottish Government 2010a,b) as opposed to chronic illness. The DH (2013, p1.) defines a long term condition as

“a health problem that can’t be cured but can be controlled by medication or other therapies”.

Whilst this is a broad definition, there are still negative associations apparent within it, such as “problem” and “can’t be cured” and it might be argued that its derivation is biomedical in its reference to medication. This definition does not account for the shift and flow of chronic illness over time (Charmaz 2006), nor the impact on biography (Bury 1982), coping with illness (Casier et al. 2011) or the place of social or cultural situations in which chronic illness is experienced (Walker 2001). However it does allude to other therapies (which might include non-medical solutions). Walker’s (2001) contention that it is unlikely that a uniform definition of chronic illness will receive universal acceptance because of the perspective of the writer is resonant, thus in the interest of pragmatics the DH (2013) statement is the chosen definition.

Further definitions are given in appendix 1 (p 211) for other commonly used terms within the study. It is recognised that these definitions also have their limitations which are debated in the appendix. However they have been adopted in the same interests of pragmatism given to the definition of chronic illness

### **1.3 Summary**

Having defined the common concepts within the thesis (appendix 1,p209) and given a rationale for the study, the following three chapters present a review of the literature relating to these concepts. This is preceded by an account of the methods used to scope the literature review.

## **CHAPTER TWO: METHODOLOGY FOR THE LITERATURE REVIEW**

### **2.0 Introduction**

Bettany-Saltikov (2012) suggests that in order to be systematic in reviewing literature the process should begin by selecting a topic of interest, and thereafter narrow the topic down to a review question. Further stages in the process should include: identifying why this is of interest and worth investigating, gains; for patients, professionals and stakeholders, the rationale for the question and deconstruction of the question, as a complex question may have more than one part to it.

At its broadest level, the topic of interest is chronic illness. This is a vast topic area which consists of multiple concepts but as a means of constructing a literature review might be themed under constructions of illness.

Loewe et al. (1998) contend that since the seventies the illness narrative has emerged as a popular literary form in relation to social construction of chronic illness. Sociological perspectives into living with chronic illness (the author's area of interest) have focused on multiple aspects of the lived experience; not only on the physical self but on aspects such as the illness trajectory (Glaser and Strauss 1968, Thorne 1993), meanings of chronic illness (Strauss and Glaser 1975, Bury 1988, 2005, Paterson et al. 2002 ), illness work (Corbin and Strauss 1985, Corbin 2003), identity (Goffman 1959, 1961, 1971, Charmaz 1983, Koch et al. 2004, Kralik et al. 2010), biography (Bury 1982, 1991), compliance or concordance (Charles et al. 1997, 1999), storytelling and patient narratives (Frank 2000). A further body of literature has focused on the relationship between people with chronic illness and healthcare professionals (Stimson and Webb 1975, Strong, 1979 , Tuckett et al. 1985, Thorne 1993, May 1995, Charles et al. 1997, Maynard and Heritage 2005, Barry et al. 2000, Mead and Bower 2000 a,b, Silverman et al. 2005, Wirst et al. 2006, Pilnick and Dingwall 2011, Fischer and Ereaut 2012 and

more recently on lay expertise (Tyreman 2005a,b), Badcott 2005, Wilson 2007). It is beyond the scope of this literature review to include all of these aspects of chronic illness. It is the latter two concepts which are of interest to me. The limitations of this approach acknowledge that in order to seek a full understanding of the chronic illness experience it should not be viewed through only one perspective. However Thorne (1993) also argues that one cannot understand the experiences of people with chronic illness without comprehending the nature, context and content of the relationships which they encounter with healthcare professionals. Thus, as the study seeks to;

“explore the perceived and observed factors that enable or inhibit partnership between young “expert” patients with Cystic Fibrosis (CF) and the Healthcare Professionals with whom they interact”

these two topics of lay expertise and interactions with HCPs in the context of partnership would seem to be appropriate areas of exploration.

This will be preceded by a biographical overview of living with cystic fibrosis in order to contextualise the study.

The component parts of the question can be broken down using the Population, Exposure, Outcome (PEO) format (Khan et al. 2003), table 1.

**Table 1: Breaking down the research question using the PEO Framework (Khan et al. 2003)**

<b>Population</b>	<b>Exposure</b>	<b>Outcome</b>
Young expert patients (age 16-35) with CF, who have lived with the disease > 5yrs, who attend a CF clinic in a specialist centre, who have transitioned from a paediatric centre more than	Attendance at the CF Clinic Consultations between patients with CF and the CF Multi- Disciplinary Team	Observed behaviours (patients and HCPs) Patients experiences of partnership HCPs experiences of partnership

1 year ago, who self-manage a range of complex technical treatments.		
--	--	--

## 2.1 Search strategy

A literature review was undertaken using the following databases: The Knowledge Network (which incorporates CINAHL, MEDLINE, ASSIA, EBSCO, HMIC, OVID EMBase, Psycinfo, Shelcat, Wiley, Social Care online, Social Work Extracts, e-library and MIDIRS) and the Cochrane Database of Systematic Reviews. Grey literature including Index to Theses was also searched and websites such as Department of Health, Scottish Government, and the Health Foundation were scrutinised to gain a perspective on user involvement and the political dimensions of the expert patient literature. Key terms are cited in table 2 (p21).

Limits were set on English-speaking, peer reviewed journals and texts published between 2000-2013, so that information was current; as earlier searches revealed little in relation to the expert patient concept. However earlier seminal literature in relation to chronic illness/long-term conditions was reviewed and included following the initial review.

A combination of thesaurus (MM/MH) and free text (TX) terms were entered into the online bibliographic databases. Truncation and Boolean operators were also used. Electronic searching was supplemented by hand searching of peer reviewed journals, and web searching to identify further grey literature, where necessary.

Primary research studies, narrative and systematic reviews of the literature and relevant position papers were included in the review. Additionally, key authors in the field were identified from the initial review (table 2, p21) and a further search was then undertaken under the author names. Several key text books were identified from this search and scrutiny of these revealed further references which were then sought out.

Papers were excluded on the basis of relevance to the context, and the limiters described above.

Edwards and Elwyn (2009) suggest there are a number of related terms in the literature around shared decision making: patient centred care, concordance, participation, partnership, informed consent, autonomy, involvement, interaction, consumerism, expert patient. Thus in applying this principle to “partnership” it was felt necessary to incorporate many of the same key words into the search strategy terms in order to capture a comprehensive overview of the literature in this area.

Bettany-Saltikov (2012) asserts that there are now many critical appraisal assessment tools available in order to take a systematic approach to reviewing the literature. The tool chosen in this study was the CASP appraisal tool (PHRU 2006, appendix 2, p212) which asks ten questions of the studies under review. Studies were eliminated on the grounds of relevance, duplication, context; (e.g. partnership or expertise between professionals rather than in relation to patients), and on quality and accessibility (anecdotal articles, book reviews, articles not in English language).

**Table 2: Key search terms and authors used in search strategy**

Examples of key words:	Articles found: Knowledge Network	Articles found: Cochrane database	Considered for inclusion: Knowledge Network	Considered for inclusion: (Cochrane)	Grey literature	Key authors (across all databases)
“Expert patient” or	124	11	29	3	1	Tyreman, Wilson,
Expert						
<i>and</i>						
patient*	256					
<i>and</i>						

partnership	438	8	25	1	3	McQueen, Hook, Coyne Cahill
<i>or</i>						
Interaction	477		30			Stimson, Strong, Pilnick, Goffman, Tuckett
<i>or</i>						
autonomy	598	13	26	1	1	Coulter, McCormack Entwistle
<i>or</i>						
engagement	299		22			Sang, Wilson, Coulter
<i>or</i>						
involvement	2234	12	13	1	2	Gabe
<i>or</i>						
negotiation	33	20	2	2		Morse, Wuest
<i>or</i>						
trust	668	1	25	1	2	
<i>or</i>						
patient centredness	105	1	41	1	7/265	Entwistle, Mead &

						Bower
<i>"Expert Patient" or patient*</i>						
and						
chronic illness	338	9	103	2		Bury, Thorne, Paterson, Kangas, Charmaz
or						
Adolesc*	42		13			Coyne, Gibson, Moore & Kirk
emotional labour	199	0	15	0	47	Hoschchild, Smith
Illness & construction*	83		5		3	Bury, Thorne, Paterson, Kangas, Charmaz

Finally following literature searching, it became evident that there were some gaps which required a further trawl of the literature to include topic areas not in the original tranch (such as normalcy, and emotional labour). This is in keeping with Timmins and McCabe's (2005) contention which states that the author may need to return to the literature as the review progresses. Further, a return to the literature was deemed necessary to review any new additions to the literature since the original search. Those



references subsequently identified for inclusion were uploaded into an electronic database.

## **LITERATURE REVIEW**

### **Living with a long term condition: cystic fibrosis and its management, constructions of illness and constructions of patients**

#### **2.2 Cystic fibrosis and its management**

Cystic fibrosis (CF) is found in Caucasians and affects almost ten thousand people in the United Kingdom (CF Trust 2013). Almost half of these are over sixteen years of age (UK CF Registry, 2013). This progressive condition is caused by a gene defect which results in abnormal thick sticky secretions in the lungs and digestive system, causing repeated chest infections and low weight (Hodson 2000). Although previously a disease of childhood, median predicted survival in 2011 is 41.5 years (UK CF Registry, 2013). This is attributed to improved screening, nutrition and surveillance; nevertheless the current median age at death in UK adult services is still only 26 years (UK CF Registry, 2013).

As a multisystem disease the burden of care is considerable and treatments consist of oral, intravenous and inhaled medicines, physiotherapy and exercise, and nutritional support through oral or enteral routes. A recent US study (Sawicki et al. 2008) calculated mean self-reported treatment burden of inhaled and oral medicines, airway clearance and exercise to be 108 minutes per day (excluding intravenous therapies). Complications of CF include infertility in males, insulin-dependent diabetes mellitus, liver disease and osteoporosis (CF Trust 2013). Most people with CF are diagnosed in the first three months of life (CF Trust 2011). Thus by the time they attend an adult clinic people with CF have been self-managing treatments for many years and might be perceived to be lay experts (Prior 2003). The rigours of treatments and accounts of illness appear to be normalised and have become an embedded part of who they are (Bluebond- Langer 1996, Gjengedel et al. 2003, Williams et al. 2009). Thus normalcy,

as a construct of chronic illness is hypothesised to impact on perceptions of illness and coping (Abbot et al. 1995, Goldbeck and Babka 2001, Sawicki et al 2008, Taylor et al. 2008, Casier et al. 2011). As a nurse specialist working with this group of young people for many years, this witnessed downplaying or minimisation of illness was an area of curiosity that warranted further exploration through the literature review.

### **2.3 Constructions of chronic illness and normalcy**

Bury's (1982) theory of biographical disruption describes how the experience of chronic illness can link to a reconceptualisation of one's identity and self-concept. Charmaz's (1983) work on self-worth and loss is closely linked to these concepts and draws attention to the spiral of losses that may impact on one's self-worth: for example loss in one area (mobility) may lead to loss in another (social isolation) and may further exacerbate feelings of low self-worth. Bury further develops the meaning of chronic illness into *consequences* for the individual (physical symptoms, financial hardship and disrupted biography) and *significance* of the chronic illness for the individual and others such as labelling, negative imagery, and effects on roles and relationships which may be positive or negative (Bury 1988). He proposes that individuals attempt to repair the disruption through legitimisation and thus find a place in society where they are accepted. Normalisation has been described as Bury (1991) as psychological bracketing of the illness as a means of coping. However he also asserts that normalcy may also mean the embodiment of treatment as part of the individual's norm.

Charmaz (2006) states that people with chronic illness find markers against which to measure themselves and give meaning to these in order to construct realities. She suggests that these measures are situational and negotiable and take on new meaning for the individual when the measures are re-interpreted and new measures or activities are adopted. Anderson (1981) argues that normalisation by parents of chronically ill children was an attempt to minimise stigma, however she observed contradictions between that which parents reported of treating the child as normal and that which was observed; such as isolating the child from play for fear of infection. She proposes that

there are different social constructions of normality for the sick and the well child, such as integration versus isolation.

The concept of normalcy emerged repeatedly in a grounded theory study (Thorne and Robinson 1989), with 70 participants with chronic illness over a three year period.

Normalcy was strongly linked to the capacity to engage in normal life, to fit in and was interpreted individually. Normalising often included downward comparisons to other people with health problems, perhaps as a means of coping; the perception being that there was always someone worse off than the individual. Thorne (1993) explains that this approach requires considerable effort with no real evidence of increase in life satisfaction. Further she argues that normalising may prevent people with chronic illness from seeing their condition realistically and moreover she proposes that ontologically there is no such thing as "normal" in a socially constructed world.

This study used secondary analysis and was derived from a study designed originally to explore relationships with people with chronic illness and HCPs, thus the fit of the data to the research question may be in doubt. To counter this Thorne and Robinson (1989) conducted subsequent interviews to validate findings.

Recent work by Casier et al. (2011) challenges Thorne's (1993) assertion that normalcy results in considerable work without increases in life satisfaction. This longitudinal study of 40 young adults with CF found that acceptance of chronic illness was related to less anxiety and depression, increased quality of life and better role and social functioning. The authors accept that the study is limited by a small sample size but conclude that acceptance of the reality of chronic illness does not mean surrendering to it, rather the use of adaptive mechanisms (e.g. normalcy) may aid coping.

In a comparative study of 60 young people with CF and their physicians, Abbot et al. (1995) found that patients graded their perceptions of illness score significantly lower than physicians. A five-point likert scale was used to measure perceived severity. Physicians' scores of disease severity correlated positively with clinical findings. 83% of patients rated themselves above average or well above average compared to 35% of

physicians. At two year follow-up the gap between patients' and physicians' perceived severity scores had widened, with the gap widest in the most severely ill patients. Findings may indicate that people with CF view health from a wider perspective than their physician, however this finding may also link to the concept of normalcy. The sample in this study may be considered to be uniform as these are regular clinic attenders who may not be typical of the total population and may exclude those on the fringes. Greenop et al (2010) are critical of the convenience sampling often adopted in CF research and argue that a truly representative sample may not realistically be achieved from within small CF populations and thus non-attenders and non-engagers need to be reached in order to overcome this issue.

Williams et al. (2009) conducted in depth interviews with 32 children with CF. The theme of normalcy (termed non-difference in this study) was analysed as having four dimensions; normal to self, normal for self, normal to others and normal for others. Disease severity was not positively correlated with children's illness experiences, perceived limitations or definitions of normality. They found that young people revised goals to avoid apparent disruption and so perpetuate the concept of non-difference (or normality). They conclude that the pursuit of normality appears to be of importance to young people with CF and that reference groups are central to sustaining perceptions of non-difference. Their work challenges Bury's theory of biographical disruption (1982) and Charmaz's theory of loss of self (1983), arguing that perhaps because this group have grown up with chronic illness, it has already become part of their identity. In contrast, Bury and Charmaz's populations were not diagnosed until adulthood, by which time they had already established biographies, identities and normalities, which did not include illness. However the Williams et al. (2009) study was cross-sectional and it is argued that perceptions of normalcy are likely to vary over time, and this could not be demonstrated here.

In their review of the literature of living with chronic illness in adolescence Taylor et al. (2008) also found a prominent theme of "being normal". Studies revealed that some

young people ceased to make comparisons with healthy peers and instead revisioned normalcy by using comparisons against people with the same condition. This is consistent with Wellard (1998) who asserts that chronically ill people fall outside norms by their failure to conform to good health. However she proposes that new norms emerge for acceptable characteristics within the illness state.

Challenging and changing these ways of coping may be detrimental (Hayes 2004), Goldbeck and Babka (2001) carried out a study which aimed to change coping mechanisms through the use of cognitive behavioural therapy in 16 families using a pre-test post-test educational intervention. Findings revealed that the children in the post-test group had decreased optimism, decreased confidence, sought out more social support and were more irritable as reported by parents. Possible explanations for the negative findings suggest that focusing on the reality of CF disease ensures that the usual strategies of minimisation (or normalisation) must be confronted. The resultant effect of this may be the stripping away of normal defences and increased anxiety and support-seeking behaviours. This study is limited by a small sample size and the authors also acknowledge that the generalisability of the sample may be limited due to the self-enrolment of participants who were already well motivated and well-adjusted to disease. Most benefit from the intervention appeared to be gained by a small subset who were seen to be less adjusted pre-test. Further, the authors argue that coping remains stable over time (Abbot et al. 2001, 2013), thus interventions may have no or little effect.

It would appear from the literature that normalcy, normalisation or non-difference are all important constructs in the management of chronic illness and may influence or be influenced by biography and constructions of illness.

## **2.4 Constructions of illness and self-management**

The concept of illness work Bury (1982, 1991), has been rebranded in recent years in the language of self-management, self-care and self-monitoring (Wilde and Garvin 2007). Rogers (2009) suggests patients have always self-managed and draws on the

literature in illness work (Bury 1991, Corbin and Strauss 1988). What has changed, argues Rogers (2009), is that self-management has been redefined from a bottom-up approach to that of top-down and has become a policy initiative which has given rise to the term “expert patient” (DoH 2001).

## 2.5 The expert patient

There is much debate in the literature about the amorphous use of this term and the definition of expert. Alternative terms such as “involved”, “autonomous”, “concerned”, “resourceful” “consearchers” or “lay experts” have been offered (Prior 2003, Shaw and Baker 2004), but to date no consensus exists on a universally agreed term. Tyreman’s (2005a, p155) position paper suggests that expertise in relation to patients is a qualitative term and is concerned

“with the way knowledge and skills are understood and applied rather than possessed as ends in themselves”.

Expertise, argues Tyreman, is in management of the illness through self-monitoring, testing and experiential knowledge rather than the technical knowledge of disease, (table 3).

**Table 3: Attributes of physician/patient expertise (Tyreman 2005a)**

<b>Patient expertise</b>	<b>Physician expertise</b>
Management	Pathophysiology
Self testing/experimentation	Diagnostic methods
Adaptation	Disease progression
Experience of the condition	Projected outcomes
Qualitative	Quantitative

Wilde and Garvin's (2007, p339) concept analysis of self-monitoring only partly concurs with this view suggesting that self-monitoring was composed of two complementary components; awareness of bodily symptoms and sensations and

"measurements, recordings and observations that inform cognition", suggesting that technical knowledge is indeed required.

Badcott (2005, p175) asserts however that whilst most patients do not have the technical knowledge to validate the basis of their treatment, what they do have is the

"ongoing personal long-term experience of illness", which is difficult to articulate to the health professional".

Chapman and Bilton (2004) make a similar point describing surprisingly low levels of knowledge particularly in relation to the genetics and treatments, in a group who have grown up with a long-term condition. They attempt to explain this as a means to control the intrusion of CF into their lives. However they express concern that the normalisation process may have implications for non-adherence to treatment.

Patient expertise may be at variance with the traditional meaning of expertise which implies craft and technical knowledge, which may be absent or even wrong in the attributes of the expert patient (Prior 2003). However it can also be seen that through self-management patients are increasingly being asked to take on technical tasks that were once the remit of health professionals (Peterson 2006), and thus technical knowledge may be associated with the expert patient in some contexts.

Prior (2003) suggests that the terminology in sociological terms has changed in an attempt to legitimise and equate lay expertise with professional expertise in order to increase lay participation in care. However it is argued that lay and expert knowledge are different and should not be polar opposites on the same trajectory. Neither one takes precedence over the other but both should be viewed as complementary in the patient/professional relationship (Kangas 2002, McLean and Shaw 2005).

Naumanen-Tuomela's Concept analysis of expertise (2001) defines the attributes of expertise as: profession, role position and title which arguably are not always those

which might be recognised in the expert patient, who may possess none of these. Further, Naumanen- Tuomela (2001) contends that the surrogate term for expertise as viewed through the nursing literature is “authority”. It is also doubtful whether this term which is easily associated with a professional would be related to an expert patient given the power differences which are still said to persist (Wilson and Mayor 2006). Consequences of expertise are said to include economic and health benefits, better relationships and effectiveness Naumanen-Tuomela (2001). However in situations where expert patients challenge HCPs there has been a resultant deterioration in relationships (Wilson 2007) and perhaps therefore a lack of effectiveness. Rogers’ (2009) critique of self-management asserts that the idealised version of the autonomous, empowered self-managing patient takes no account of the roles that biography, context and condition play in long term conditions (Charmaz 1983, 2002, Bury 1991, Thorne 1993, Koch et al. 2004, Mays 2006). For example patients may place a higher importance on fulfilling social roles than compliance with symptom control. The author recalls a patient who refused a lung transplant on the grounds that he would lose state benefits, a view which the medical team found difficult to reconcile as their assumption was that being healthy was more important than being without a regular income. This example highlights the conflicting agendas which may be present between HCPs and patients.

## **2.6 The young expert patient**

LTCs are often associated with midlife and old age. The author comes from a background of working with young people with a LTC and hypothesises that expertise is also present in this group. Many are diagnosed at a young age and may have built up a repertoire of skills and knowledge which informs their self-management. This phenomenon of LTCs in young people raised an issue for the author as to whether the “expert patient” definition is influenced by age, and whether partnership is occurring between young “experts” and HCPs and was thought to merit further exploration.



A review of the literature in this area suggests that there may be barriers associated with partnership with young people with LTCs. These include parental intervention and control (Coyne 2006), life stage developmental issues, (Alderson et al. 2006), power issues with HCPs (Corlett and Twycross 2006a, Coyne 2008) and gate-keeping (Mauthner 1997, Woodgate 2001, Irwin and Johnson 2005).

Alderson et al. (2006) purposively selected a sample of 15 children from urban and suburban areas with type 1 diabetes, aged 3-12 years, to explore their experiences of partnership working with adults using observation at clinics and semi-structured interviews. The researchers found that some "ordinary" children were well in advance of child development theories in relation to their stage of ability. Children as young as nine were calculating carbohydrates and adjusting insulin accordingly. This was confirmed by their parents and physicians. Children aged four were able to self-diagnose hypo and hyper-glycaemia. The authors are cautious about generalising from a small group with a specific condition; however they argue that only a few examples are required to show that at least some children are functioning above that expected of their developmental stage, indicating the need to take cognisance of children's views. This is echoed by Brady (2009) who concluded in her grounded theory study of 22 hospitalised children aged 7-12 that children had an understanding of meaningful care and were able to communicate this to others. The sample was drawn from a large teaching hospital and involved children of varying cultures and with a wide variety of diagnoses. The author was unable to achieve data saturation due to time constraints. Staff were involved in identifying participants which may have influenced the sample. A further limitation of sampling was the exclusion of non English-speaking children.

MacDonald and Greggans (2008, 2010) followed six families' experiences of befriending in young people (aged 8-19 years) with cystic fibrosis (CF) over 18 months. Young people and parents were interviewed individually and befrienders interviewed via a focus group. Findings revealed a sub theme of "young people as experts of their condition". This expertise was displayed through their use of technical language when discussing their condition, as well as their knowledge of the disease and how it affected them. Furthermore, through self-monitoring young people were able to detect subtle

changes in their conditions and could anticipate the need for intervention. This expertise was often challenging for their befrienders who did not understand the nuances of the disease or indeed the technical jargon which the young people used. This was a small-scale study whose findings may be attributable only to this group with a particular long-term condition; however the theme does support previous findings of the presence of expertise in young people with a LTC (Alderson et al. 2006, Coyne 2006).

This will be further explored in the proposed study, albeit through a slightly older age group (16-35 years).

## **2.7 Summary**

In summary, CF is a progressive, multisystem disease, which is burdensome in terms of the treatment demands placed on individuals and families. Despite these significant demands, the literature supports that, similar to other groups with a long term condition, people with CF downplay the severity of the disease and normalise their condition. This may have a positive impact on coping. Unlike previous research on biographical disruption in chronic illness (Bury 1982), CF appears to become part of the biography, perhaps because of its diagnosis for the most part in early childhood. Most people with CF have been self-managing increasing technical treatments for many years and may be considered expert patients, even those of relatively young age. It is clear that there is no universal agreement on the term “expert patient”. Expertise is not a concept easily applied to both HCPs and patients and is not bound by age. It would appear that the use of the term “expert patient” has evoked anxiety and discomfort among healthcare professionals who may feel threatened by its usage, (Shaw and Baker 2004, Daiski 2004, Corlett and Twycross 2006b, Wilson 2007). This concept will be explored further through the research questions. This is preceded by a review of the literature in relation to partnership and the HCP/ patient relationship.

## **CHAPTER THREE: PARTNERSHIP**

### **3.0 Introduction**

This chapter will explore the literature around the models, attributes, perceptions and outcomes of partnership between patients and HCPs and highlight some of the barriers to partnership. The chapter will conclude with justification of the proposed research.

### **3.1 Defining partnership**

Defining partnership and its attributes according to Gabe et al. (2004) is still under negotiation but as discussed earlier, the term has become fashionable in UK Policy documents (SE 2007, LTCC 2010, DH 2010, SG 2010a,b, SG 2013) and in health and sociological literature.

Charles et al. (1997, 1999, 2000) propose three models which conceptualise partnership in the patient- physician interaction: the paternalistic model, the informed model and the shared model. The latter two models shift autonomy and responsibility towards the patient but it is suggested these approaches may be more demanding of resources; particularly time to develop rapport and development of decision aids to facilitate partnership (Gabe et al. 2004, Entwistle 2004, 2006a,b, Entwistle and Watt 2006, Entwistle et al. 2008a,b, McIntosh and Runciman 2008, O'Connor et al. 2009, Coulter and Collins 2011). Further, it is suggested that patients and physicians will slip into different models depending on the severity of the patient's condition and the complexity of treatments (Charles et al. 1999). Thus in life-threatening situations a move to paternalism may be required in the short-term. This move towards patient-centredness is also occurring in consultation contexts which limit physicians to one diagnosis per patient per visit, due to high patient volumes which may restrict communication, constrain relationship-building and lead to misdiagnosis or overlooking the most salient problem (Lovell et al. 2011).

Partnership as a term has been offered as a contrasting alternative to a paternalistic model of care; from that of compliance, which is professionally defined (Wilson, 2001, Dawood 2005, Greenop et al. 2010), to therapeutic alliance or concordance (appendix 1). Non-compliance may be viewed negatively by professionals despite evidence that patients often make sound judgements about treatments (Shaw 2007). Contrastingly, concordance envisions a person-centred world where treatment goals are negotiated through working in partnership. This language of partnership is clearly visible in recent white papers and policy documents which use terms such as “partnership”, “mutuality”, “empowerment” and “equity” with recurring frequency in relation to patients carers and families (SE 2007, LTCC 2010, DH 2010, SG 2010b, SG 2013).

### **3.2 Attributes of partnership**

Partnership as a concept has been analysed in key papers in the nursing literature (Cahill 1996, Charles et al. 1999, Coulter 2002, Gallant et al. 2002, Bidmead and Cowley 2005, Hook 2006). Whilst commonalities appear to exist in the literature regarding the attributes of partnership (table 4), Hook (2006) suggests the mechanism which transforms HCPs into effective partners is unclear. Furthermore, partnership may also be influenced by interpersonal factors, including the language and culture of the partners, gender, concordance, developmental stage, parental involvement and practitioner conduct and experience (Heritage and Maynard 2006, Pilnick and Dingwall 2011, Lovell et al. 2011, Maddison and Beresford 2012).

Coulter (1999) sees partnership as involving establishment of shared goals, recognition of mutual respect, shared decision making and an absence of hierarchy. Calnan and Gabe (2001) and Waterworth and Luker (1990) question however, whether patients are ready for the responsibility of shared decision-making. May (1995) suggests that there is empirical evidence to support the active resistance of patients in partnership. This

paper draws on literature that is now more than twenty years old, before the birth of consumerism in healthcare, and thus may not represent current views.

**Table 4: Attributes of partnership** (Adapted from Hook 2006).

<b>Attributes</b>	<b>Associated terms</b>
Shared decision-making	Negotiation, mutual goals, shared decision making
Relationship	Mutuality, reciprocity, alliance
Professional competence	Expertness, empowering, supports change
Shared knowledge	Mutual learning, common understanding
Autonomy	Self determined, expert in own care, ownership
Communication	Two-way, honest, open, confidential
Participation	Engaged, monitors, takes charge
Shared power	Equal, engages in trade-offs, shared control

### **3.3 Perceptions of partnership: HCPs**

Whilst there is a perception by HCPs of partnership working with patients, it is suggested that published work in the last ten years highlights that this supposed shift towards partnership is often still rhetoric rather than reality; with nurses being involved in covert surveillance of clients, (Wilson 2001, 2007), exerting power over carers (Henderson 2003, Coyne 2007a, 2007b) and seeing expert patients as a threat to their sense of professional integrity (Henderson 2003, Shaw and Baker 2004, Wilson et al. 2006, Wilson 2007).

Wilson (2001) conducted a study with five child health nurses in New Zealand exploring their perceptions of partnership during home visits with new mothers using discourse analysis. She interviewed nurses twice about their day-to-day practice. Findings revealed that nurses perceived the development of rapport with mothers as essential for a good relationship. However Wilson (2001) argues that this rapport served to allow nurses to engage in gentle surveillance of mothers. Thus partnership was not seen as equal but had implications for power relations with the nurses covertly scrutinising mothers in their own homes. Wilson (2001) argues that power was also perceived by nurses as multi-directional, with mothers engaged in withholding information or not telling the truth. Mothers were not interviewed in this study, and thus partnership was only viewed from the nurses' perspective. Wilson (2001) concludes by suggesting that if partnership is truly the aim within the nurse-patient relationship then attempts to foster honesty by both parties should be made. Further she suggests research needs to be undertaken with patients and families to gain both perspectives; which is the design proposed by this author in this study.

Henderson (2003) conducted interviews and participant observation with 33 nurses and 32 patients in four teaching hospitals in Australia using a grounded theory approach. Findings revealed that whilst nurses acknowledged patients' need for information and shared decision making, they were reluctant to share or collaborate, resulting in non-egalitarian care which was contrary to the partnership model. The sample was specific to surgical and medical wards and there is limited information on the status of the patients (in terms of "expertness"). Nurses in the sample were of mixed experience but it is not stated whether there were differences in information sharing between novice and experienced nurses.

In a grounded theory study (Wilson et al. 2006) found that nurse specialists were more willing to facilitate self-management practices than their more junior colleagues. This finding is unsurprising given that senior nurses are less rule-bound and more likely to

work autonomously and more confidently than junior nurses (Benner 1984, Manley et al. 2005, Wilson et al. 2006, Wilson 2007).

Stoddart and Bugge (2012) used a grounded theory methodology to examine the nature of negotiation between 18 practice nurses and 18 patients in four health centres. Non-participant observation, field notes and semi structured interviews were used to collect data on the process of negotiation between nurses and patients. Using constant-comparative analysis key categories relating to negotiation were identified as: navigation, socio-cultural characteristics and power and control.

Navigation began with establishing rapport and a sense of connection between the two parties and was concerned with the formal etiquette between them, such as patients waiting to be told to sit down. Socio-cultural characteristics referred to locating parties in their social world; e.g. age and nurses' adaptation of language according to their perceptions of social class of their patients. Power and control in negotiation referred to the sense of anxiety experienced by patients regarding loss of dignity during the consultation, the outcome of the consultation, preparation for, (having a bath before the consultation) and scrutiny during the consultation. The authors conclude that their findings highlight the place of dignity and respect as central to the nurse-patient relationship during social interactions. Further, they endorse the dynamic process of negotiation of power and responsibility in the nurse-patient relationship. The study is limited by its lack of heterogeneity in ethnicity and gender.

Stevenson et al. (2000) examined a model of shared decision making (Charles et al. 1997) which has similarities to Hook's (2006) attributes of partnership. These are that both the patient and the doctor are involved, both parties share information, both parties take steps to build a consensus about the preferred treatment and an agreement is reached on the treatment to implement. They analysed 62 audio-taped patient consultations with 20 General Practitioners (GPs). Patients were interviewed before and after the consultations and GPs were interviewed after the consultation by

semi-structured interview. Six months after the consultations GPs were invited to attend a feedback session. The authors concluded that the first two characteristics of the model were not generally seen in the data. They found that even when there appeared to be sharing of information, patients perceived that their views were not taken seriously; a view echoed 15 years earlier by Tuckett et al. (1985). GPs cited pressures of time and organisational structures as barriers to achieving shared decision making. Sampling of patients was diverse in terms of age (3 months -84 years) and gender (29 women, 33 men) but not in terms of ethnicity (60/62 white) There was an absence of older GPs in the study and gender division is not stated. It is not clear whether observation formed part of the methods, thus there is no information on non-verbal communication between the parties. The authors concede that their study was only a snapshot of what may have been a long-term relationship between patient and GP, thus relationship-building and information sharing may have been happening at previous points in the relationship. Nonetheless they argue that absence of information-sharing in a sample of self-selecting GPs who were interested in communication probably means that the practice is not widespread elsewhere.

### **3.4 Perceptions of partnership: patients and families**

Coyne (2006) concluded from a review of studies of hospitalised children that the practice of listening to and involving children and young people in care decisions by health professionals was not widespread. In a grounded theory study Coyne (2006) observed levels of participation in care and subsequently interviewed children (n=11), parents (n=10) and nurses (n=12) across four paediatric wards in two English hospitals. Findings revealed that children had varying experiences of being involved in care. Those who were involved found this made them feel happier and respected as individuals with rights. Children actively sought out information from parents, nurses and peers as well as from literature. However children felt their own opinions were underused, reporting lack of consultation in decision-making, poor explanation-giving and of their opinions being paid "lip service" by HCPs. This made them feel



depersonalised or “non-persons” (Goffman 1961). Parents in the study highlighted their children as the best experts on their condition and emphasised that this be respected by HCPs. Whilst in the main nurses acknowledged that children’s voices should be heard, they cited barriers of involvement such as age, parental involvement and feeling threatened by children who were very knowledgeable. Further they found it difficult to provide examples of how they involved children in care.

Although this study took place over four sites, numbers of participants were small and children were hospitalised for a variety of reasons which included treatment of chronic conditions and planned surgery. Not all children had chronic illnesses. Unstructured observation took place for up to three hours at a time in each site, but the total number of observed periods are not recorded, nor the limitations of this method. The paper alludes to the details of the children in a table which is not to be found in the article and thus we are not fully aware of the age, gender or demographics of the participants. In spite of these limitations, Jolley (2006) in a response to the study highlights the similarities in his own findings from a PhD thesis he undertook with children in the 1950s. Whilst Jolley (2006) concedes that some things have changed for the better in paediatric care, he also deduces that much has not, despite a number of “chattering class” reports that we should listen to children.

Thorne et al. (2000) undertook a secondary qualitative analysis to examine attitudes between healthcare professionals and expert patients with two different chronic illnesses; diabetes mellitus and environmental sensitivities (sometimes referred to as chronic fatigue syndrome). In both studies participants explained their experiences of illness in the context of relationships with health professionals over time. With some exceptions almost all participants described health professionals’ pervasive disbelief in their patients’ competence to make decisions for themselves, creating a culture of distrust and defensiveness. In addition participants perceived that health professionals clung to the role of expert within the consultation, resulting in conflict with regards to management. Further, participants perceived health professionals to be engaged in practices of controlling information and punitive gatekeeping, such as refusal to sign

certificates for sick leave. As stated, this study used data from two independent studies which were both concerned with gaining insider experiential knowledge of living with chronic illness. The first study used a think-aloud methodology and followed participants over a year to ascertain their decision-making methods, whilst the second used in-depth interviews to construct illness narratives. Data was applied to a second set of research questions after the initial studies and may have lost some trustworthiness in its translation across languages, cultures and new diagnostic categories.

### **3.5 Summary**

The increased emphasis on partnership in the policy and nursing and sociological literature suggests an intention to shift from a perceived paternalistic model to that of a more mutual, egalitarian prototype. However the literature suggests that barriers to equality within partnership still exist and include perceived attitudes to power sharing; for example lack of trust and defensiveness, (Thorne et al. 2000, Henderson 2003, Coyne 2006), perceived lack of investment in resources (Charles et al. 2000, McIntosh and Runciman 2008, Lovell et al. 2011) and gatekeeping (Coyne 2006). Barriers also exist from patient perspectives, through withholding of information or lack of truth-telling (Wilson 2001). However this is an area which is said to be worthy of further exploration as much of the literature in this area is viewed from a professional rather than patient perspective (Wilson 2001). The proposed research aims to address this gap by seeking views from both parties on their perceptions of partnership.

Thorne et al. (2000) suggest that when individuals with chronic illness “enter the arena” of negotiation for their healthcare services they are inevitably thrown into complex relationships with healthcare professionals. These relationships they suggest, are rarely scrutinised and often poorly understood. It is the intention of this research to explore these interactions between patients and HCPs in relation to partnership. This is preceded in chapter four by a review of the literature in this area.

## **CHAPTER FOUR: SOCIAL INTERACTIONS BETWEEN PATIENTS AND HEALTH CARE PROFESSIONALS IN THE CONSULTATION**

### **4.0 Introduction**

This chapter will explore the literature of social interactions between patients and HCPs over the past 30 years. Key themes will be highlighted and analysed and the chapter will conclude with a rationale for the proposed study.

Social interactions between HCPs and patients and carers have been an area of interest for more than 60 years (Parsons 1951, Goffman 1959, 1971, Stimson and Webb 1975, Strong (1979), Tuckett et al. 1985, Waitzkin 1991, Lewin et al. 2001, Mead et al. 2002, Bensing and Verhaak 2004, Kurtz et al. 2005, Heritage and Maynard 2006, Pilnick and Dingwall 2011, Fischer and Ereaut 2012). Key themes that emerge from this body of work are the persistence of medical domination and asymmetry in the medical encounter and the continued ritualisation of that encounter.

### **4.1 Asymmetry in the consultation**

Strong (1979) conducted an observational study between 52 staff, 27 children (patients) and their parents across three children's hospitals in two large cities in Scotland and the USA. State and private clinics in America were also accessed to achieve comparison across different contexts and systems across the two countries, (however in some cases the same children were also seen in different settings). The Scottish branch of the study was longitudinal with patients being seen as many as 12 times over three years and included 1020 observations. A further 100 were undertaken in an American city and were completed in three weeks. Most observations took place in paediatric out-patients clinics but some were in ward rounds with children and staff (but not parents). Observed periods varied from less than a minute to over an hour. Two observers took verbatim written notes which they then recorded and transcribed.

In addition some key staff were interviewed and informal discussions between staff (students, staff and the researchers) were recorded verbatim in writing. Data were analysed using constant comparative analysis (Glaser and Strauss 1968).

Findings from Strong's work revealed that despite the variety across consultation settings, the nature of participants and their diagnoses, cultures and length of interactions,

“the ceremonial order of the consultations was remarkably invariant”(p38).

This “bureaucratic format” (Strong (1979) which involves politeness, formality, and control of emotions, was consistent across all of the medical encounters and predominated over the other formats; charitable, private and clinical.

The theme of asymmetry in the consultation described the imbalance of power within the bureaucratic format, whereby parents were both excluded and controlled.

An additional finding from the results of Strong's observations was the absence of the children's voices in the study. He ponders how it is that a study which observes the interaction between parents, professionals and children excludes any consideration of the children and in an attempt to answer this suggests that there may be two reasons for this. Firstly that the children are represented at clinic by another, usually a parent but that more significantly their exclusion in his study is due to the fact the children themselves were excluded in the consultation process. As argued earlier, this perhaps was the norm in Western society 40 years ago (Strong 1979). However despite legislation (United Nations Convention on the Rights of the Child-UNCRC, 1992), the Children Act (2004) and the appointment of a Children's Commissioner in 2004, Coyne's (2006) and others' work suggests that this may still be an issue in society today (Gabe et al. 2004, Lee 2007, Coyne 2010).

In Strong's study, interviews took place with paediatricians thus gaining only one perspective from the three observed. Staff comprised paediatricians and therapists and did not account for other professionals who may have played a part in the child's care, nor all branches of paediatrics.

Strong acknowledged the crucial role played by the nurses in the clinic setting, whose duties included gate-keeping, preparation of patients through physiological measurements, gleaning background information, assisting the doctors in procedures, the ordering and flow of the clinic, organising patient follow-up and calming distressed patients or parents. Nevertheless nurses were not interviewed and thus their stories were left untold.

Other limitations of the study include the presence of observers (Hawthorne effect) which may have influenced the behaviour of those being observed, although Strong argues that the clinic setting constituted a highly public place and hence the presence of multiple persons during consultations was the norm rather than the exception to the rule. Thus it would be unlikely that an observer would have prompted a change in behaviour. It is also argued that verbatim note-taking is highly labour intensive and may give rise to problems with accuracy given the sheer volume of material to be recorded. Furthermore, one might argue that trying to observe and record other phenomena such as non-verbal communications, rules of engagement and detection of background activities would be very difficult in addition to capturing the written word.

Strong's (1979) work draws on Goffman's (1971, 1975) dramaturgical work on impression management and performance. Goffman describes the world as a stage and an individual's part in that as self-presentation and role performance. Impression management is portrayed through front stage behaviour; observing the rules and standards of decorum. Failure to adhere to the roles and rules results in unintentional disruptions, inopportune intrusions, *faux pas*, *gaffes* or *bricks* - resulting in embarrassment and jeopardy of the portrayed individual or team image (Goffman 1971). Further, Goffmann (1975) goes on to describe frame analysis: the subjective context where performance takes place; the clinic for example, which is governed by written and unwritten ceremonial and social rules and *situated roles* (for example doctor and patient). Strong (1979) suggests that *situated roles* are a part of something bigger called *role format* which refers to the coherent whole (the organisation and its overt

rules rather than the individual) so that more than one *role format* may be used in an encounter. Thus in the medical encounter the bureaucratic (polite) and charitable (the uncovering of a person's moral essence) formats might be present in the same encounter. *Role formats* are concerned with the overt not covert behaviour which are often at odds with each other. For example the overt behaviour in the bureaucratic format might observe the HCP controlling emotion and treating the parent with politeness-termed medical gentility (Parsons 1951), only to make judgements covertly about their lack of intelligence and poor standards of self-care to colleagues (Strong 1979).

Over 30 years later Pilnick and Dingwall (2011, p.1374) report that empirical studies of the medical consultation continue to point to the

“remarkable persistence of asymmetry”.

However they argue that asymmetry is not necessarily problematic and lies at the heart of the medical consultation. They are critical of the stance that some sociologists take of the consultation as a power struggle for dominance which leaves the patient silenced, suggesting that if patients are not troubled by asymmetry then neither should be the sociologists. They caution that this dominance may be evidenced by the data analysis approaches used rather than the actual encounter in the consultation.

Whilst the literature acknowledges that patient satisfaction may be improved through the adoption of patient-centred approaches (Lewin et al 2001, Duncan et al 2010, Lee and Lin 2010), the evidence on improving health outcomes is at best, mixed (Hibbard 2009, Ovretveit 2012). Moreover Pilnick and Dingwall (2011) argue that a patient-centred approach for all denies the notion of patients as individuals, and needs to focus less on normative and more on individualised approaches. They continue that the focus on person-centredness has been driven by a physician-deficit model resulting in new practices and tools to drive medical education and communication, such as the Calgary-Cambridge guide (Kurtz et al. 2005). However despite best efforts in this area over the last 30 years Pilnick and Dingwall (2011) attest that as patients are still not routinely leading consultations or specifying preferred outcomes then perhaps it may be time to

question this strategy. Furthermore they concur with Horne et al (2005) who assert that paternalism is fundamental to any system in which medicines' access is controlled for public safety and where accountability rests with the prescribers. Thus, they argue that the limits for reform need redefinition rather than a call for more participatory decision-making.

## **4.2 Decision-making in the consultation**

Collins et al. (2005), in a study examining unilateral and bilateral decision making approaches in the patient-doctor consultation, found that even where bilateral approaches were used which encouraged shared decision making and offered choices, patients did not always express preferences or make decisions but left it to the doctor. Entwistle (2000, 2004) found that patients' perceptions of who made decisions in the medical encounter were less important to them than the process whereby issues were discussed. Also important was the ethos of health encounters which included respect for persons, and facilitating their views, a point echoed by Greenop et al. (2010). Whilst recent work has shown that patients would prefer professionals to take the lead in decision making this should not be interpreted as a non-desire for involvement in the process (Edwards and Elwyn 2009).

In a longitudinal study of 614 patients with Type 2 diabetes, patients were assessed at baseline and 4 monthly intervals over a year using self-report standardised scales measuring trust, perceived support, satisfaction, and autonomy preferences (Lee and Lin 2011). In addition HbA1-C was measured to determine blood glucose levels. Lee and Lin (2010) found increased support for autonomy within patient-physician relationships was positively correlated with patient's trust in physicians, perceived satisfaction and mental health-related quality of life. Autonomy support was not however associated with improved glycaemic control. Suggested explanations for this include a discrepancy between patient preferences for decision involvement and behaviour. Moreover, they suggest that despite the will for shared decision-making,

patients may lack the necessary skills and information to contribute significantly to this process. Limitations of the study were concerned around generalisability of the sample, who were older, poorly educated, and had poor glycaemic control at the outset of the study. It is suggested that there is evidence to support that older, less informed patients take a more passive approach to decision making and this may have been the case in this sample. Nevertheless Lee and Lin (2010) state the need for situationally-determined support for autonomy preferences, where physicians adapt the degree to which they facilitate power-sharing, responsibility and decision making, to that which patients' desire. They conclude that it is the ethical consideration of respect for individuals which should receive greater attention rather than the normative consideration of participatory decision making. This point is echoed by Lovell et al. (2011) whose review of communication factors affecting the patient-clinician interaction includes organisational sources and healthcare systems; the clinical environment and training of clinicians, rapport and trust, language and culture and practice experience.

Hubert et al. (2013) piloted a communication tool designed to allow patients to quickly express their concerns at consultations with CF physicians. Discomfort and social and professional life were the most popular domains for discussion. New domains were added based on patient feedback and included: fatigue, study abroad, self-esteem and anxiety, recreation and procreation and contraception. Only 50% of patients wished to address treatment issues which appears to confirm that patients have different priorities to physicians, but it is argued that systems and contexts rarely allow for these issues to be raised.

### **4.3 Consultation settings**

Gabe et al. (2004) suggest that the physical, legal and bureaucratic settings should also be seen as part of the setting where partnership occurs. They claim that the format suggested by Strong (1979) still shapes what is achievable with many paediatrics clinics



set in a poor standard of accommodation. Further, they suggest that despite legislation giving a voice to children, paediatric partnerships have been slower to move to a partnership view and more research is required in this area, particularly in routine settings (such as that proposed in the planned study; the outpatient clinic). They propose that this tardiness may be because the partnership involves more than two parties; the child, parent and physician. They contend that Charles et al. (1999) suggestion of coalitions between two of the three parties at a given time may be a useful way forward. For example the physician may form a coalition with the child to reduce parent pressure or alternatively with the parent to persuade a child to take medication. Each of these coalitions implies the use of power and persuasion in the patient-physician interaction. Hewison (1995, p76) proposes that the

“conceptualisation of power is manifested and observable in interpersonal encounters”.

However perhaps due to the power differences that exist within the patient-physician interaction, requests from patients are not always directly stated but instead given indirectly as cues (Levinson et al. 2000).

#### **4.4 Use of cues in the interaction**

Tuckett et al. (1985) analysed 1302 consultations between 16 General Practitioners (8 in a control group and 8 in a comparative group) and patients at 108 surgery sessions in order to examine communication and sharing of ideas in the medical consultation. Specifically they focused on four areas to investigate: the diagnostic significance of the problem, the doctor's treatment/action, the doctor's preventative action and consequences of the illness and its treatment. Thereafter they interviewed 328 individuals in their own homes within a few days of the consultation.

Findings revealed during consultation were that GPs tried to state their views and provide a rationale, but rarely invited discussion of social and psychological implications for the patient. They also found that whilst patients did not always make their view explicit, GPs did not encourage or welcome cues and at times evaded or interrupted patients who were trying to express a view. At interview most patients were able to recall most of the key points of the consultation correctly, but almost a third missed out on one key point. Consultations were largely found to confirm patient views, although this was less likely in younger patients, mothers with children or patients from ethnic minorities. There were no differences between the study group and the comparative group in the extent to which they shared information. Tuckett et al. (1985) contend that the ethos of the medical consultation in this study perpetuated the stereotype as the patient as passive and ignorant and the doctor as powerful expert. They assert that patients need to be treated

“as the experts they believe they are” p.217.

That is not to say that they possess the same type of expertise. The authors suggest that there needs to be a meeting in the middle, so that patients integrate the biomedical model into their own schema and doctors are open to establish patients’ ideas in order to help the doctor know what to explain.

This study is now 30 years old. Other limitations of the study include the cross-sectional nature of the consultations. Many patients have on-going relationships with GPs which might be difficult to gauge in a single session as opposed to a pattern of unfolding events. Secondly this was a self-selected sample of GPs who were interested in communication, and thus they may not be a representative sample. Further, findings were based on a record of audio events, and thus non-verbal communication could not be observed which would have added to the richness, interpretation and veracity of the data. Finally the inferences drawn from the audio recordings were dependent on subjective rating judgements. These rating scales however were tested on a random sample of cases by independent raters who then came together and were largely in agreement.

Despite the age of the study, more recent literature shows similarities in patients' use of cues within the doctor-patient interaction (Stevenson et al. 2000, Barry et al. 2000, Levinson et al. 2000, Salmon et al. 2004, olde Hartman and van Ravesteijn 2008, Eide et al 2011). Perhaps in an attempt to preserve the ceremonial order of the consultation, patients rarely directly state agendas. Instead they may use cues, non-explicit remarks that can enclose a special meaning (olde Hartman and van Ravesteijn 2008).

In a study of 116 randomly selected transcribed audio consultations Levinson et al. (2000) found that in over half of the consultations patients used one or more cue. At least 60% of these cues were emotional in nature and in the majority of consultations physicians missed the opportunity to react to these. Cues about patients' concerns were often embedded in biomedical discussions and Levinson et al. (2000) caution that physicians may be so bogged-down in addressing these that they miss them. They suggest that physicians need not attend to every patient cue but rather respond to cues in those encounters where patients repeat cues or appear to cry for help. Reasons for non-attendance to cues are given as physicians feeling uncomfortable, lack of skills training in this area and an anxiety that attendance to cues may result in longer consultation times. This was refuted in the study as those encounters which acknowledged cues were shorter than those which did not. This is borne-out by other literature (Butow et al. cited in olde Hartman and van Ravesteijn 2008). This study was limited by several factors; the small predominantly male physician sample which limits generalisability, absence of observers which could not take account of non-verbal communication which may have addressed cues (such as hand holding) and the lack of a link between the addressing or missing of cues and patient outcome.

Strategies to avoid addressing cues in the consultation include blocking cues, use of closed questions, normalising cues, offering reassurance which fails to address the cue and medicalising somatic concerns by offering further investigation (Salmon et al. 2004).

Barry et al. (2000) used a case study approach to explore patients' agendas by interviewing them before and after consultations with GPs and by listening to audio-

recordings of the consultations. GPs were also interviewed. At consultation many items which had been deemed important in the interviews were unvoiced. Patients behaved differently in interviews than in the consultations, referring more to biomedical constructs than social constructs and appeared to have less autonomy in consultations than in interviews. Limitations of this study include self-selection of GPs interested in communication and lack of observation of the consultation which may have revealed more than from the audio recording alone. Despite the GPs' interest in communication with patients, results of this study do not appear to fit with the attributes described by Hook (2006) of equality and mutuality, suggesting that some GPs continue to focus on patients' biomedical rather than social worlds which can result in patients leaving consultations with unanswered questions.

A recent study (Eide et al. 2011) found that patients used a large number of cues and concerns which included emotional distress, in their interactions with advanced practice nurses. More cues than concerns were expressed when there was lack of empathic responses from nurses. Contrastingly, high empathy was associated with greater expression of concerns than cues. The authors suggest that the high level of concerns expressed may be down to the advanced empathic skills of the nurses as well as the time given to each patient. They advocate the use of patient-centred approaches for the enablement of disclosure of cues and concerns.

Fischer and Ereaut (2012) conducted a review of the literature and interviews with experts in the field of clinician-patient relationship and interaction. Following this they conducted a series of workshops with patients, doctors, nurses and Allied Health Professionals (AHPs) to create fresh perspectives on their findings. These findings were then explored in workshops with change agents and policy makers. The authors suggest that the current consultation model needs remodelled and firstly needs to take account of patients' priorities. They describe the current model as engagement in a dance

“where only the doctor knew the steps and could hear the music” p48.

Thereafter they suggest consideration should be given to classification of the “problem” as tame (definable and solveable) or wicked (having multiple definitions and solutions). Physician and patient may have shared or competing priorities in order to accomplish a solution to the problem. Principles to achieve this might include competition, co-ordination, negotiation and co-evolution but are constrained by resources, language and culture. They propose strategies to improve the consultation such as: making consultation processes more explicit, helping patients prepare for the consultation, gathering feedback on the consultation from patients afterwards, including planning the setting, meeting with receptionists and other personnel, audit of consultations through video and use of technology to change the dynamic between physicians and patients.

#### **4.5 Summary**

The literature concerning the nature of social interactions between patients and HCPs evidences the preservation of the theme of asymmetry in the relationship. Reasons for this may be linked to historical models of paternalistic healthcare (Strong 1979) and the historical place of the child in society as “seen and not heard”. Further explanations may be attributed to the setting where interactions take place (Gabe et al. 2004) which may not be conducive to a patient-centred approach and anxiety from HCPs that patient-centredness takes more time (Levinson et al. 2000). Competing priorities between HCPs and patients are also said to be a factor in the consultation (Fischer and Ereaut 2012). It is suggested that HCPs do not always attend to patients’ cues or concerns (Levinson et al. 2000, Eide et al. 2011) and use strategies such as blocking or, normalising cues, or medicalising cues by offering further investigations (Salmon et al. 2004). Finally it is argued that asymmetry may not be problematic for patients who may not wish to lead the consultation (Pilnick and Dingwall 2011), rather it is the process of discussion within the consultation that appears important.

## **4.6 Summary of the Literature Review**

The literature review has demonstrated that calls for reform from paternalism to partnership evidenced in the language of policy for increased self-management practices, empowerment, mutuality, recognition of lay expertise and a partnership approach to care, are not evidenced through the literature on partnership and patient-clinician interactions.

In over 30 years of healthcare research on the clinical consultation, it would appear that the consultation is still biomedically driven, takes place in a bureaucratic format in settings which are not always conducive to partnership and are influenced by unequal power and control, surveillance and lack of consideration of developmental stage, culture and language. With some exceptions, patients perceive that HCPs distrust their abilities to make decisions and engage in practices of surveillance, control of information and punitive gatekeeping. Young people may feel excluded in the consultation process through protectionism and parental involvement but there is a dearth of literature regarding their views of partnership. They feel their opinions are underused; report lack of consultation in decision-making, poor explanation-giving and feel their opinions are paid “lip service” by HCPs.

Investment in partnership is said to be costly in terms of resources of time, building rapport and tools to aid informed decision making. HCPs worry that attending to patients’ cues and concerns in the consultation may result in longer consultations at a time when they are already under pressure of time, a fact not borne out by the literature. Positive outcomes of partnership include an increase in patient satisfaction, feeling happier and respected and increased disclosure of concerns in the consultation. Negative outcomes include lack of trust, emotional distress and a feeling of not being taken seriously. As yet there is little evidence of improvement in health outcomes linked to patient-centred approaches.

The expectancy that the move from a paternalistic model of care to one of involvement which would envision patients leading consultations, setting agendas and specifying outcomes has not yet borne fruit. Instead patients voice cues and concerns which may or may not be heard. It is suggested from the literature that not all patients want autonomy or to self-determine outcomes. What appears to be important to patients is the *process* of the consultation and the *ethos* of respect within the consultation. With regard to *expert patients* the term remains ambiguous and poorly defined. To date, most studies have focused on the expert patient as an adult who has acquired a long term condition in mid or later life and suffers biographical disruption. This notion is challenged in young people with a genetic long-term condition such as cystic fibrosis who have embedded this as part of their biography. Normalcy as a coping mechanism appears to be a pivotal part in a person's construction of chronic illness regardless of age and intervention to disrupt this strategy may result in poorer coping. Some level of expertise appears to be present in young people with chronic illness as well as older adults, as evidenced by their experiential knowledge of self, abilities to manage technical procedures and use of technical language. However there is debate as to the labelling of these skills as "expertise". HCPs may feel threatened by lay expertise and worry that responding to cues and concerns may increase the consultation time in an already stretched system. It can be hypothesised that expertise is present in young people with LTCs as well as those further on in the lifespan. Little is yet known on how this expertise is viewed and used during consultations between young people with a LTC and the HCPs with whom they interact. HCPs may need to take more account of patients' priorities in managing their LTC, which are not necessarily the same as the professionals, and subsequently engage in consultation and negotiation with them in order to plan person-centred care. It is this aspect of consultation and negotiation (partnership) in the context of the young expert patient that warrants further exploration through the proposed research.

Much of the nursing literature cited in the review focuses on partnership in the nurse-patient relationship as viewed from a nursing or medical perspective; thus there is a

lack of perspective which views partnership from the patient/carer's viewpoint. Further, most of the studies cited discuss that which HCPs report rather than that which has been observed. This assumes that what HCPs report is a true representation of what actually happened in the encounter. The sociological literature examining patient-physician interaction uses conversation analysis or patient/physician interview to elicit the dynamics of the consultation. Few have used observation techniques, and thus cannot draw inferences from non-verbal communication in the consultation.

This study seeks to redress these gaps in the literature by exploring the nature of partnership between both young expert patients and HCPs as witnessed through observation of their social interactions and deconstruction of these observations via semi-structured interviews. Thus the aim of the study is:

**To explore what strategies are used by young "expert patients" with Cystic fibrosis and healthcare professionals to maintain and negotiate partnership?**

Sub-questions:

1. How do young "expert patients" and the healthcare professionals with whom they engage perceive partnership?
2. What are the perceived outcomes of partnership from the patients' and healthcare professionals' perspectives?
3. What are the perceived and observed factors that enable or inhibit partnership?
4. How do young "expert patients" report their use of past experiences of Interactions with healthcare professionals to negotiate care management strategies in future encounters?

The case for the methodology to support this study will be detailed in chapter five.



## **CHAPTER FIVE: METHODS**

### **5.0 Introduction**

This chapter will discuss the epistemological stance, theoretical perspective and methodology for the study. Thereafter the methods employed for sampling, data collection and analysis will be outlined, concluding with discussion of ethical issues and rigour.

### **5.1 Researcher perspectives on “knowing” and “being”: (epistemology and ontology)**

In addition to the research evidence detailed in the literature review, experiential knowledge (as a nurse specialist working in the context of long-term conditions) and personal beliefs have influenced the choice of paradigm and subsequent methods. It is the intention to set forth these beliefs and a rationale for the choice of paradigm and methods in the following section together with the challenges encountered during this process. These challenges included examination of personal beliefs in relation to truth and knowledge to help develop an understanding of their impact on the collection and interpretation of data. A further challenge for me was to demystify the terminology used in formulating theoretical frameworks in order to offer such a framework for the planned research.

This study, while firmly located in the qualitative, interpretative paradigm, is informed by Social constructionism and Symbolic Interactionism (SI). The aim of this chapter is to discuss these terms in full and explain how the research framework adapted from Crotty (1988) and the methods fit with this approach.

## 5.2 Exploration of beliefs

Maxwell (2005) suggests the motivation for pursuing a study is linked to three goals: personal, practical and intellectual goals. Personal goals are often linked to experiential knowledge (Denzin and Lincoln 2000, Maxwell 2005), and an awareness of how personal goals may influence a study is essential in order that the researcher can declare through which perspective they view the research. Proctor (1998) asserts that exploring personal beliefs may assist the development of understanding of philosophical principles such as the relationship between ontology (the nature of reality) and epistemology (the theory of knowledge), (Crotty 1988). According to Proctor (1998), individuals rarely take time to do this in everyday life.

Berger and Luckman's (1971) explanation of the ontological assumption that beliefs about reality are created in social interaction, are subjective, and play a part in constructions of people and institutions (social constructionism), linked to the researcher's own world view and experiential knowledge and form part of the proposed research framework. Capturing this knowledge (epistemology) requires the researcher to respect the differences between people while seeking to understand and find meaning in experience from multiple perspectives, (interpretivism), (Weaver and Olson 2006). Thus, theory emerges inductively.

Social constructionism contends that meaning is constructed by humans, as they engage with the world they are interpreting. There are multiple realities and senses of self in participants' worlds and sense is made of these worlds through the meaning given to the language and symbols used, within the context of culture (Burr 1995, Holloway and Freshwater 2007). Humans actively participate in, rather than passively accept from others, their constructions of reality (Holloway and Freshwater 2007). This world will contain multiple realities as people may perceive and describe the same situation differently, influenced by their past experiences and the influences around

them (Silverman 2005). This also resonated strongly and is best illustrated by way of an example.

This example relates to the multiple perspectives (economic, psychosocial, biomedical) through which patients and physicians prioritise living with a long term condition (Bury 1982, Charmaz 1987). From experience it is recalled that the priority for one patient was to opt out of a transplant despite their deteriorating health as it might result in a long-term loss of sickness benefit. For the physician the priority was seen as resolution of health through transplant (and consequently an ability to resume employment).

This example illustrates the variance in beliefs and values (ontology) between the two parties. Thus social constructionism argues that ontologically there is no one universal truth; rather it is constructed according to beliefs, values, contexts and experiences (Crotty 1988). Epistemologically the researcher would attempt to find meaning in the different stances taken by the two parties and give explanations (interpretivism).

Thus in this study the interaction between young expert patients and the HCPs might be perceived very differently by both parties and will be explored through the ontology of social constructionism. This then forms the first stage in the proposed theoretical framework.

### **5.3 Making sense of Theoretical Frameworks**

Crotty (1998) offers a four stage framework to illustrate the elements of the research process. These are the *methods* employed, the *methodology* which governs the choice of methods, the *theoretical perspective* which underpins the methodology and the *epistemology* that informs the theory. Maxwell (2005) refers to the *conceptual framework*, which contains the research problem, and should connect to a *research paradigm* such as constructivism, positivism, realism and pragmatism. Dyson and Brown (2006) suggest the hierarchy in the research process makes a distinction between *research strategies*; the broad organising features of research design and *research methods*; the data collection techniques. Above these terms in the hierarchy are seated

the different *philosophical traditions* that underpin the *research approach*, such as positivism and interpretivism.

As can be seen from the previous paragraph different terms are used to describe similar concepts, which may be very confusing for the novice researcher (Welford et al. 2011). Thus a challenge for me was to try to make sense of these terms then ensure that the proposed study could be justified philosophically and methodologically and not pigeonholed to make it fit one of the boxes (Woolcott 2002).

Whilst Crotty's framework appealed as most accessible it was noted that there appeared to be no "column" in the framework for ontology-only epistemology-and this created confusion for me and warranted further exploration.

Having used Grix's (2001) definitions of terms as the theory of *knowing* (epistemology) and the nature of *being* (ontology), it was important to explore why the latter appeared to be missing in Crotty's framework and where this left me in finding a fit within my own conceptual framework. Mack (2010) was instrumental in filling this gap by re-emphasising the ontological and epistemological assumptions inherent in the interpretivist paradigm. Thus it became clear that a paradigm consists of ontological and epistemological assumptions. Grix (2001) expands on this, contending that approaches such as constructivism and objectivism are ontological positions which will influence how one undertakes research. Hence ontology affects epistemology (Welford et al. 2011), which in turn affects the methodology (Mack 2010). Thus it became clear to me within the chosen framework the epistemology of Interpretivism was informed by the ontology of social constructionism.

Epistemologically then this study draws upon interpretivism (which recognises that knowledge is interpreted subjectively) and ontologically on social constructionism which acknowledges that peoples' realities are different. This is presented in table 5 which has adapted Crotty's framework to make provision for the place of ontology within it.

**Table 5: Research framework for this study**

Framework (Adapted from Crotty 1998)	Applied in this study
Epistemology	Interpretivism (informed ontologically by Social Constructionism)
Theoretical Perspective	Symbolic Interactionism
Methodology	Descriptive Interpretivism
Methods	Interviews, Non-Participant Observation

As illustrated above, whilst grappling with the terminology of research frameworks it became apparent that there is not always one best fit into which to box one's own study. Woolcott (2002), Maxwell (2005), Denzin and Lincoln (2000) and Dyson and Brown (2006) assert that adoption of one single paradigm is not mandatory. Forcing research into a particular paradigm can be stifling and compel the researcher into choosing methodologies which may not be suited to the question under exploration (Patton 2002, Denzin and Lincoln 2000). Rather than agonising over theories, Woolcott (2002) contends that something might be gained by playing with more than one at a time. Smith et al. (2011) suggest that to the purists the danger of mixing theoretical methodologies or "slurring" has been viewed as seeking academic credence, whilst resulting in a lack of congruence between the aim, design methods and analysis of data. However, Sandelowski (2000) asserts that the adoption of a generic approach to qualitative research can enhance the credibility of a study's findings because the researcher is more likely to reflect participants' experiences by staying true to the raw data than if they were more concerned with its philosophical underpinnings. This stance was also advocated by Thorne et al. (1997), who offered a methodology of Descriptive Interpretivism which they suggest acknowledges the position of the researcher as interpretive and which further accepts the constructed and conceptual nature of the health-illness experience. It is this methodology which is proposed.

Crotty (1998) also warns against plucking a research approach off the shelf, rather he argues one should create one's own research process, drawing on the work of others

and engaging in a running conversation with them. Maxwell (2005) similarly asserts that there are many different paradigms within qualitative research and the researcher need not adopt one single paradigm or tradition, but may combine different aspects of these. He suggests that the choice of paradigm will be based on one's experiential knowledge and assumptions as well as the best fit for the proposed research. Thus the proposed approach, where a researcher may

“work within and between overlapping perspectives and paradigms”

(Denzin and Lincoln 2000, p6) was appealing.

However it is argued that it is not the intention in the proposed study to bridge paradigms, as clearly I position myself in the qualitative domain. Qualitative research adopts an emic perspective, an insider's point of view, and is said to be naturalistic and person-centred (Holloway and Freshwater 2007), a view to which I wholly subscribe. The “insiders” in this study are young experts and healthcare professionals. As the study seeks to explore the nature of partnership between the young experts and HCPs it is essential that both parties' views are explored and assigned meaning. Further, the interpretive role of the researcher and the context in which the research takes place are seen as central to the investigative enquiry. Whilst other methodologies were considered; such as case study (Stake 1995, Sackett and Wennberg 1997, Jones and Lyons, 2004, Flyberg 2006, Luck et al. 2006, Yin 2009) and ethnography, (Muecke 1994, Cutcliffe and Ward 2004, Roberts 2009), it was acknowledged that although *elements* of both these methodologies could be seen in the proposed research, neither of them were a true fit and their selection may have been as a result of trying to pigeonhole the methodology to fit the framework (Woolcott 2002), rather than attempting to stay close to the data (Sandelowski 2000). The broader methodology of Descriptive Interpretivism recognises that the search for “truth” has the potential to be applied, but remains answerable to reconsideration in light of new concepts, contexts and new ways of understanding (Thorne et al. 1997).

The intention therefore is to build a framework within the qualitative paradigm that draws on different theoretical perspectives, (such as Symbolic Interactionism)

methodologies, (Descriptive Interpretivism) and methods, (observation, interviews) which all contribute to the framework to form a cohesive whole. These subsections of the framework are outlined below.

## **5.4 Theoretical Perspective**

Symbolic Interactionism (SI) as a theoretical perspective is not unlike social constructionism in that it views the world through the use of language and symbols and takes into account the importance of culture, interrelationships and community (Crotty 1998). However from a methodological perspective whilst focusing on subjective meanings and the symbols by which they are represented, SI emphasizes the importance of context, and asserts that an individual and their context are inseparable; meaning changes according to the context for the individual and impressions may have to be "managed" differently in different contexts (Charon 2009). Thus to study human behaviour the researcher must

"return to the empirical social world" (Blumer 1969, p34).

The context in this study may be seen as both persons, the group of "expert" patients and the HCPs with whom they interact and place, and the setting where the interaction occurs (the out-patient clinic). The choice for this setting has both strengths and limitations. Firstly the out-patient clinic is the only setting where patients and the full team of HCP's can be observed in their individual and group interactions. This "sub culture" can be said to have its own language and covert and overt practices or symbols, (Strong 1979) which can be observed and explored. However, a limitation of this setting may be that it is perceived as being HCP territory as opposed to neutral ground. Thus power imbalances are apparent simply by placing patients in a context that renders them situationally dependent and gives HCPs standing and authority (Gallagher et al. 2005, Cohen et al. 2007).

A further tenet of SI is the concept of “self” developed by James (1842-1910, cited by Benzie and Allen 2001), who stated that an individual has more than one “self”. Further, Goffman (1959, 1961) declared that life can be viewed as a theatre with the individual participants taking on the roles of actors. Thus the role (self) of the expert patient or indeed the HCP might be very different than if that person was playing the role of father or employer (context dependent). Goffman (1961) contends that when an individual appears before others, they have many motives for trying to control the impression they give in front of others and/or receive of the situation. This may for example include keeping a professional distance in the doctor/patient relationship in order to minimise patient anxieties (Morgan and Krone 2001), but may come at a cost of emotional labour (Erickson and Grove 2008, Dinesen et al. 2008).

Goffman (1975) further suggests that everyday life is made up of delineated “worlds” where the “world” is a mode of experience fleshed out by adherence to the rules of a frame or occasion. A frame is described by the stable rules of its operation; whatever the circumstances of any particular enactment. What guides conduct is an individual’s place with respect to the social relations of productions of a ritual world. These social relations-including the rules of the frame-are explored in the context of the out-patient clinic between young expert patients and the HCPs with whom they engage.

Crotty (1998) suggests that while we interpret the world around us, we do not do it object by object; we are already born into a world with meaning, which has been previously constructed and is context and culture dependent. It is suggested that the client group (young experts) and HCPs are already socialised to the world of illness and healthcare and this is typified by the jargon they use (Peterson 2006, MacDonald and Greggans 2008), and the support networks they resource to share experiences (Charmaz 2002, Peterson 2006). It is the intention to further explore the meaning of these interactions in relationship to partnership.



## 5.5 Critique of SI

SI has been criticised for its inability to provide clear-cut procedures in which to carry out research; i.e. for its lack of a clear cut method (Kuhn 1964). However this has been countered with the view that it takes an holistic approach rather than a prescriptive methodology and as such is open to different methodologies (Swanborn 2010). Fine (1993) suggests that over the years there has been a splintering of the philosophical approach, such that it has become blended with other interpretive and realist paradigms. This however may have its advantages as such diversity may breed new knowledge and theory. Fine (1993) further acknowledges that domains of emotion-work and experience, and creation of self have now become recognised as having associations with SI and these domains struck a chord with the author in this study and linked to my experiential knowledge (Crotty 1998).

Other criticisms of SI include viewing nursing purely through a sociological lens such as symbolic interactionism, when clearly a holistic view would also take account of biological cultural and psychological factors (Benzies and Allen 2001). This is acknowledged, but as the purpose of this study is to focus on *interactions* between HCPs and young expert patients, SI is an appropriate stance to adopt. However the author would contend that in reporting the results of these interactions it would be impossible not to refer to biological cultural and physiological issues, as one assumes these will all form part of the recipients' worlds. Therefore an holistic approach is proposed incorporating all of these "worlds", drawing on SI and a Descriptive Interpretivism methodology.

## 5.6 Methodology: Descriptive Interpretivism:

As described above Descriptive Interpretivism is viewed as a broad methodology which sits within qualitative methodology. Thorne et al. (1997) suggest that traditionally descriptive qualitative nursing research was forced to locate itself within one of three recognised methodologies: phenomenology, grounded theory or ethnography.

Grounded theory was eliminated at the outset as it was not my intention to generate new theory from the data (Glaser and Strauss 1968); rather the intention was to describe the phenomenon of partnership.

Phenomenology is described by Speziale and Carpenter (2007, p.77) as

“as much a way of thinking or perceiving as a method”

and seeks to describe the lived experience. Whilst elements of interpretive phenomenology resonate, such as the researcher as instrument (Speziale and Carpenter 2007), the process of bracketing was perceived as particularly challenging due to my previous history in the unit. Furthermore, whilst phenomenology may have been suited to a question such as the lived experience of having cystic fibrosis, the sample comprised two groups (HCPs and young people with CF) and was concerned with the *interaction* between these groups. Thus Phenomenology appeared not to fit wholly with the research questions.

Ethnography is defined as the study of races (Grix (2001) and typically the researcher immerses themselves in the culture, language and day-to-day life of the population under study. Issues around this methodology usually centre on the nature of the close relationship between the researcher and the researched and are commonly associated with thick description (Cutcliffe and Ward 2004). Whilst in my previous post I perceived I was immersed in the culture as an insider, many years have passed since then. It may be argued that I now sit somewhere between the etic and the emic perspective (Holloway and Freshwater 2007) and thus am not fully immersed in the culture as I once was. Additionally the pragmatics of full time work and part time study do not permit a “full blown ethnographic study” (Grix 2001). This methodology was therefore also rejected.

In light of these considerations a broader methodology of Descriptive Interpretivism (Thorne et al. 1997) is preferred. Thorne et al. (1997) suggest that nursing as a science is concerned with the application of practice and interdisciplinarity and need not always be constrained to fit traditional methodologies. Descriptive Interpretivism, they argue,

gives freedom to examine methodological questions in the context of nursing science which

“loosens the bonds of traditional methods and may help build on its own epistemological foundations” (Thorne et al. 1997, pp 172).

As this methodology purports to create sound interpretive descriptions of how people experience meanings of health and illness; in particular, in the context of partnership, it would appear to be a good methodological fit with the study in question.

## **5.7 Summary**

The first half of this chapter has provided an overview of my journey in pursuit of the choice of epistemology, ontology and methodology to be employed in the study. These are informed by my own beliefs and values as well as from a review of the research literature. It is acknowledged that the framework could consist of other theoretical perspectives appropriate to the interpretivist paradigm such as phenomenology or ethnography. It has been argued however that Symbolic Interaction as a theoretical perspective is a good fit for the study which aims to explore the strategies used by young expert patients and HCPs to negotiate and maintain partnership. This will be executed through observation of their social interactions and subsequent interviews and will be explored in the second half of the chapter.

## **5.8 Methods**

This section will critically discuss the rationale for methods linked to the study design and present the methods used within the research process. This will be followed with a discussion of proposed approaches to ensure rigour of the research process. Finally potential ethical issues are identified and strategies offered to address these.

## **5.9 Design**

Yin (2009) suggests that triangulation through multiple methods of data collection can provide a more convincing and accurate case study. However if one subscribes to an interpretivist epistemology then defining a concept as accurate would appear to suggest that there was only one truth and it has been argued that a constructionist ontology would oppose this stance. Stake (1995) however asserts that researchers have ethical obligations to ensure they minimise misinterpretations and the use of additional observations can allow revisions of an initial interpretation in qualitative research. Further, Moran-Ellis et al. (2006) contend that the purpose of triangulation may not always be to claim validity of findings but to reflect variances in perspectives of the same phenomenon. In subscribing to this approach, non-participant observation and semi-structured interviews were used to collect data on the phenomenon under exploration. These are discussed in turn.

## **5.10 Observation**

Observation methods are usually classified as participant or non-participant and the choice is dependent on the research question and the contextual setting (Mays and Pope 2006).

One disadvantage of observation is the Hawthorne effect, where individuals behave differently precisely because they are being observed, (Landsberger 1958). It is suggested however that professionals are too busy to behave in a way that is very different from their norm (Mulhall 2003), but steps such as familiarising oneself with the clinical team and environment through attendance at meetings and clinics may help to prevent this effect.

As a previous staff member in the unit where the research was carried out, familiarising myself with the team was not an issue for me. However the potential issue of over-familiarity and bias which might influence access, recruitment, sampling, methods and

veracity of the data due to my previous position was declared throughout the research process using reflection and field notes (see Results Chapter, p93-97).

Yin (2009) suggests that time and cost are further limitations of the observation method and this may have an impact on the sample size. Initially this study proposed to explore views of two groups of expert patients, those with CF and a second group with diabetes. However it became clear early on in the planning process that the time involved and the amount of data gathered would far exceed the maximum scope (in terms of wordage) of the research study. Thus a decision was made in discussion with peers and supervisors to limit the sample to only young people with CF (Yin 2009). It is acknowledged that in making this decision what may have been sacrificed is the heterogeneity of data across two different groups with distinct conditions (CF and diabetes), as opposed to one more homogenous group. However it can be argued that heterogeneity still exists within the sampled population due to the diversity in degrees of illness, gender, age and social context (as demonstrated in the findings section). Furthermore, several of the CF group also suffer from CF related diabetes mellitus; thus there may be some areas of commonality between the two populations. Finally it is accepted that in real world research there is often a trade-off between what is desirable versus

“the financially affordable and the practically do-able” (White 2012, p20).

### **5.11 Structured/Non-Structured Observations**

Observation methods can be classified into structured or unstructured (Polit and Beck 2004) and participant or non- participant (Grix 2001).

Structured observations are used to quantify a phenomenon which is decided in advance of the encounter and are appropriate for large scale studies examining measurable data and testing hypotheses (Holloway and Jefferson 2000b, Mulhall 2003). However, as this study aimed to examine the nature of interactions which are not measurable, it seemed more appropriate to adopt an unstructured approach but to use

a framework to guide the observation. Initially a framework by Mack et al. (2005) was proposed. This was rejected by the ethics committee as not sufficiently detailed, thus an alternative was selected: the Calgary-Cambridge guide (Kurtz et al. 2005, appendix 3). This served as a means of loosely categorising the consultation in terms of communication skills (opening, closing) and appraising the biomedical and social dimensions of the consultation. This model has been widely adopted in over 60% of UK medical schools (Silverman 2007) and has been translated for use worldwide. It is intended to integrate process and content of the communication encounter. It has also been criticised as too long, reductionist and too prescriptive (Silverman 2007). However according to Silverman (2007) it was never the intention that it should be formulaic and used as a tick box step by step approach; rather he suggests the tool should form an aide memoire and be used flexibly according to context; which was also my aim in this study.

Whilst using a tool in an unstructured observation may appear contradictory, Grix (2001) contends that as with many components of research, it is possible to combine two approaches providing interaction with empirical data is minimised. Thus, whilst the observation was classified as “unstructured” the Calgary-Cambridge guide provided a systematic lens through which to frame the consultation episodes and was arrived at through consideration of the literature. The tool allowed analysis of the interaction with regard to the biomedical versus holistic approach to the consultation as well as observing the different communication styles used, such as opening and closing the consultation.

Non-participant unstructured observation usually involves a passive role for the researcher who should not directly influence events, but merely observe them (Grix 2001). However Mulhall (2003) suggests that in unstructured observation, the researcher may adopt differing roles from non-participant to fully participant. Field notes can help to assist the researcher to contextualise the process and assist with reflexivity and the audit trail (Silverman 2005).

There is much debate around the process of note-taking with Silverman (2005, p251) contending that “there is no one right method”. Richardson (2000) suggests that they should be categorised into: observation notes what is seen and heard; methodological notes, messages on data collection; theoretical notes, hunches on what the researcher is seeing/thinking; and personal notes, doubts, anxieties and pleasures. Roberts (2009) advocates that field notes should be transcribed and analysed alongside interview data in order to assist transparency and contextualise the data. I proposed a combination of methods to assist the process of transparency, but primarily use of a reflective diary which would detail personal highs and lows, theoretical musings as well as a record of supervisory meetings, and action plans. Observation notes were recorded during non-participant observation and transcribed and analysed alongside the interview data, (see example appendix 3, p213).

## **5.12 Interviews**

Face-to-face interviewing has been cited as the most common method in qualitative research to explore people’s contextual experiences and the meaning they hold (Holloway and Jefferson 2000a). Interviews are useful when accessing narratives which describe people’s worlds (Silverman 2005). Charmaz (1990) suggests interviews are particularly appropriate in studies whose focus is on long term conditions where individuals’ biographies are recorded. The interview as a method is aligned to the ontology of social constructionism where people’s worlds are believed to consist of multiple realities and where knowledge is not given, but created and negotiated (Kvale 1996). Thus it is an appropriate fit for the chosen epistemology of Interpretivism. Terms used to describe different models of interviews (structured, unstructured, in-depth) are according to Arthur and Nazroo (2003), often used inconsistently. Generally however unstructured interviews are said to follow a broad agenda, whereas structured interviews may be more fixed in the approach to questioning (Patton 2002). Morse and Field (1996) contend that the semi-structured interview is useful when the interviewer knows most of the questions to ask but cannot predict the answers. As the study

focused on partnership and the questions were informed in part by the attributes of partnership as informed by the literature review, it was felt that semi-structured interviews were an appropriate choice of method. A topic guide was constructed which reflected areas highlighted in the literature review (appendix 4, p216).

Legard et al. (2003) warn that the unpredictability of data that may be disclosed during the course of an interview may require special handling by the researcher. This may require the researcher to withdraw from the situation or at the very least may present an ethical dilemma (Duncan et al. 2009). Legard et al. (2003) contend that the researcher should be reminded that the participant has consented to be interviewed, however when the interview takes an unexpected turn, confirmation of this consent should be reaffirmed. Ballamie and Johnson (2011, p725) assert that all ethical challenges are “amplified by uncertainty”.

They suggest that whilst acknowledging the perceived notion of the participant as vulnerable, it should be recognised that researchers too, may face being placed in vulnerable positions throughout the research encounter. They counter that whilst projects need to be developed flexibly to adapt to the challenges, not all challenges can be anticipated in advance, which can leave the researcher feeling emotionally drained (Gregory et al. 1997, McCosker et al. 2001, Dickson-Swift et al. 2006).

One strategy to address these challenges is to risk-assess the potential pitfalls in advance of the process and put in place mentoring and support structures at institutional and informal levels for neophyte researchers and others associated with the research (Dickson Swift et al. 2008). These issues will be further addressed in the ethics section (p85).

Legard et al. (2003) contend that while a good interview may appear naturalistic, it should also bear no resemblance to everyday conversation. In reality they assert that there is much stage-management involved in the process and the success of the



interview depends to an extent on the qualities of the interviewer. These include curiosity, creating rapport, being able to think and process quickly, being efficient and carefully preparing. Mason (2002) adds that the researcher uses a range of skills during the interview process such as being alert to contradictions, considering how the responses relate to the research questions and deciding how to follow up and phrase subsequent questions as well as keeping an eye on equipment, managing distractions and interruptions. In order to address some of these issues a combined pilot observation and interview were planned prior to formal commencement of the study.

### **5.13 Pilot Study**

Van Teijlingen and Hundley (2001) give a comprehensive list of the reasons a pilot study might be useful, including testing of instruments, feasibility of the study, and identifying logistical problems, such as familiarisation with recording equipment and the software and hardware required to download, transcribe, manage and store the raw data. Further, it can highlight the difficulties of trying to observe, record, note take and at times interview subjects in the out-patient setting, which is noisy and involves multiple personnel in the consulting room at the same time. Finally it can highlight the length of time that would be required for observation, interview and transcription. A pilot study was therefore undertaken to address these issues. An issue that arose during the pilot concerned whether to use of the data that were generated through the observation and interview. Watson et al (2007) acknowledge that whilst the main purpose of a pilot is to test out the methods and other practical aspects of the study, data that is produced is incidental unless there have been no changes to the original protocol. This is echoed by Connelly (2008) who asserts if little has changed in the pilot then the data should be used in the parent study (as long as consent is given). In the study no changes were made to the instruments, or the setting, thus some quotations from the pilot study were included in the main findings.

The pilot study also helped me become familiar with the setting where the observations and interviews took place and the tools employed (recording device, observation

framework and topic guide). In reality the setting was busy, noisy and took place amongst multiple comings and goings in the clinic. The pilot also served to help estimate transcription times which unsurprisingly took longer than estimated.

#### **5.14 Sample**

Non-probability sampling schemes are used widely in qualitative research in order to study the population of interest (Proctor and Allan 2006). Maxwell (2005) argues that the term “sampling” is in itself problematic in qualitative research as it implies a representativeness of the sampled population which is at odds with the one of goals of qualitative research; capturing heterogeneity in the population under study. Instead he prefers the term “purposeful selection” (p88), which includes settings and activities as well as persons in the selection process. Stake (1995) contends that the overarching goal of selection of the case should be to maximise what can be learned, which is not always linked to the typical case but also gives insight into the unusual. However Morse and Field (1996) argue that describing the sample can be problematic for the qualitative researcher because the number and type of participants cannot always be predicted at the outset of the study. Patton (2002) argues that all sampling within qualitative research is purposive, but has further classified within this term sub-categories such as homogenous and maximum variation sampling and typical case sampling.

I attended a team meeting with the HCPs to inform them of the study before its commencement; hence they were aware of the study’s existence. Furthermore, I went to great effort at the preparatory sessions with the team to assert that those selected should be a heterogeneous group in order to achieve variation and maximum learning (Stake 1995) and reduce bias. It was acknowledged that I would to some extent rely on the CNS’ to alert patients to the study’s existence and there may be potential for them to invite only “popular” patients (as defined by them) to take part in the study. Thus it was suggested that within the inclusion criteria a range of patients be approached i.e.

perceived to be of different academic abilities, social class, gender, to vary in their adherence to treatment and who crossed the whole age range (16-35 years).

**Table 6: Inclusion and exclusion criteria**

<b>Inclusion criteria</b>	<b>Exclusion criteria</b>	<b>Comments</b>
Aged 16-35 years	Under 16, over 35 years	Consent issues if under 16. not considered young patients if over 35
Must have transitioned from paediatric clinic more than 1 year ago	Transitioned within the last year	Must have formed a relationship with HCPs and suggest this takes a while (e.g. If only seen 6-monthly)
Diagnosis of CF		LTC which requires a significant amount of self- management
Male or female		
Must have lived with the disease for 5 years or more		Suggests a level of experience of living with a LTC Some CF patients may also have more than

		one LTC (e.g. diabetes) this would not exclude them as long as managing one LTC for >5 years
Must attend a specialist clinic in Edinburgh area	Attend clinics out-with Edinburgh	Logistics of travel and access for researcher
Views themselves or are viewed as expert patients- have to self-manage a range of treatments (medicines/insulin/physiotherapy/diet) Uses skills such as self-monitoring, testing and adapting treatments using experiential knowledge. (Tyreman 2005a)		Patients may self-select, and deselect as appropriate. CNS views will be asked for assistance in recruiting patients.
Must attend at least 2 Consultations with CF team per annum and have attended within 6 months	Attends consultations less than twice annually	Suggests is engaged with HCPs on a relatively regular basis

### 5.15 Recruitment

A two-pronged approach was adopted A self-selecting group of “young expert patients” (Tyreman 2005a) aged 16-35 years, (Berger 2005) of either gender, with CF and who attended clinics in a large city and the health professionals they encountered there would be sampled (Table 6, p74).

Once ethical approval was gained, a sample group of patients was identified through posters placed in the ward and out-patient waiting areas (appendix 5, p215).

Participants were invited to contact me by telephone or e-mail via a number/address listed on the poster. Those that did were then seen in out-patients or in the ward area by me to discuss the study further and were issued with information sheets. Those still interested were issued with letters of invitation and consent forms, with stamped addressed envelopes to take away and return should they wish to engage with the study (appendices 6,7, p217-220). Participants were then asked to identify the health professionals they encountered in their regular consultations as part of the management of their LTC, and they too were approached by letter (appendix 8, p222) and invited to participate in the study.

Specialist CF Nurses (CNS') were also involved in the recruitment process. Using the out- patients appointment diary CNS' identified potential patients who fitted the inclusion criteria each week in advance of their appointment. During their visit, patients were invited by the CNS to participate in the study. They approached eligible patients to the study and gave out information sheets to those patients who expressed interest. These patients then contacted me to discuss the study further, were offered information sheets, letters of invitation and consent forms in the same way as those who self-selected. This group were also asked to identify the HCPs who were then invited to participate.

Both parties (patients and HCPs) gave written consent for me to observe the consultation. Further written consent was gained in order to interview each party individually after the consultation. Participants could opt to consent for only one stage of the process (the observation or the interview) or both (appendix 7, p221).

In order to ensure objectivity in recruitment of participants I did not plan to be involved in the selection process. The role a researcher assumes with participants may affect the relationship and subsequently influence the research outcome (Dowling 2006). As a previous CNS in the speciality some of the older patients may have been known to and

may have felt some obligation to participate (Carr 1994). However Morse and Field (1996) contend that the amount of rapport and trust developed with the researcher may be important in gaining rich information. Alternatively Yin (2009) contends that investigators must understand the issues in advance in order to test them against propositions, but this may lead to bias if researchers are not open to alternative findings. Thus it was felt that working with a new set of unknown participants may help illuminate other findings and rival explanations.

Stake (1995) suggests that the first criterion in sampling is to understand the case and maximise the learning from it. Logistics such as time and access to participants are important considerations for the researcher and it was expected that data collection would take place over a four month period (appendix 9, p225). The aim was to achieve a sample of 5-10 patients and the corresponding health professionals they encountered.

**Table 7: Example of recruitment strategy**

Expert patient with CF, Seen 3-monthly at Out-Patients
Each visit patient sees CNS, Consultant, Dietitian, Physiotherapist, Pharmacist (separately)
Potential to observe 5 consultations in one clinic visit
Potential for 6 interviews (1 patient, 5 HCPs)
Logistics (time, space, setting up equipment) suggest realistically manage 3 observations and 1 interview with HCP at each clinic visit

## 5.16 Tools

Observations, interviews and field notes were recorded using a digital encrypted voice recorder and a topic guide (appendix 4, p214) was used to guide the interview process

which was guided by the pilot study. As discussed, the Calgary-Cambridge guide (Kurtz et al. 2005, appendix 3, p213) was used to frame and analyse the observation event. This is an updated version of the original tool which integrates content and process. HCPs and young expert patients were interviewed separately and data was audio-taped and transcribed verbatim. I transcribed the majority of the interviews and observations, but employed an assistant to help with this. This is debated in the analysis section.

### **5.17 Data Analysis**

The issue of who should transcribe continues to be contested as it is argued that research is situational and consequential thus transcription should only be carried out by those undertaking the research (Tilley 2003), as important insights may be missed once the tape is handed over to an external person. This view is echoed by Evers (2011) who argues that transcription should not be seen as a chore but as an analytic process in itself. However as White (2012, p20) argues,

“in all social research there will always be a trade-off between: ..... the financially affordable; the practically doable .....”

thus the decision was made because of time constraints to employ a transcriber to assist me.

Skukauskaite (2012) asserts that transcription, like the process of analysis in qualitative research, is socially constructed. Thus the claim that transcripts are “true representations” may depend on the lens through which it is observed and the interaction between the interviewer and interviewee.

Britten (1995) advocates that researchers need to critically analyse their style of interview and seek support and feedback from supervisors. Supervisors were given a copy of an interview and transcript to comment upon, and feedback was given. However, this is an area that I recognise as requiring further development (see reflexivity, P84).

Following transcription the raw data was imported in to a computer software package; NVivo 9.2 (QSR 2012) and analysed using "Framework" (Ritchie and Lewis 2003, p82).

### **5.18 Computer-Assisted Software in Data Analysis**

A personal goal for me was to develop the skills necessary to use a computer-assisted qualitative analysis software package. Pope et al. (2000) caution that whilst there are advantages of using software to organise and manage the laborious process of data handling it is not necessarily a time-saving exercise. It may however demonstrate a systematic approach. Whilst software packages are designed to help manage the data, it is the researcher who must do the work of analysing it, (Spencer et al. 2003, Bergin 2011, Seers 2012). Seers (2012) warns that it is easy to be overwhelmed by the sheer volume of data that is collected; rather than being immersed in it one can feel instead like drowning. Spencer et al. (2003) contend that there is much debate on the pros and cons of using computer-assisted packages, with the benefits including the ability to handle large amounts of data and improvements in rigour through consistency of approach. This is countered by the opposing view that the speed and power of these packages might encourage the researcher to cut corners. Further it is argued that epistemologically there is the potential for loss of engagement and fragmentation of data as a result of using software which is not the case in manual coding (Pope et al. 2000).

### **5.19 Thematic Analysis Framework**

According to Swanborn (2010, p114)

"data collection and data analysis ... are not sharply separated in time but go hand in hand in a permanently changing order".

This is echoed by Silverman (2005) who asserts that data should be analysed as it is gathered. Spencer et al. (2003) assert that in the qualitative research domain, there are



no agreed rules or procedures for data analysis; variation occurs according to epistemological stances, the focus of the research and the aims of the analytical process. As the study is a qualitative descriptive study and was not based upon a particular theoretical proposition, it is reasoned that data analysis was viewed as an iterative inductive process (Pope et al. 2000). Thus it was imperative to be open to the emergence of themes which had not been preconceived. In addition consideration would also need to be given to *a priori* themes (e.g. perceptions of partnership) which might be conceived as arising from the research question (Bazeley 2007).

“Framework”, the tool of choice in the study, is a matrix-based analytic method which was derived in the 1980’s (Ritchie and Spencer 1994) and has been adopted widely in qualitative research (Pope et al. 2000). The rationale for its use is partly pragmatic; the author had prior knowledge of the tool, and wanted to develop this further. Additionally the framework approach is a staged scaffolded systematic approach to analysis (Smith and Firth 2011) which stays close to the raw data whilst

“allowing the researcher to move back and forward between different levels of abstraction” (Ritchie and Lewis, 2003, p220).

As a pragmatic learner (Honey and Mumford 2006), this type of approach suited me, as a staged approach helps with the intimidating task of moving from data management to descriptive and explanatory accounts (Smith and Firth 2011). Perhaps more importantly however was its fit with my ontological and epistemological position of staying true to the data whilst demonstrating transparency (Ritchie and Lewis 2003).

Framework consists of three stages (table 8) which will be discussed in turn.

### **Table 8: Stages of the Framework process (Ritchie and Lewis 2003)**

1.	Data management: becoming familiar with the data by reading and re reading
----	--

for recurrent themes (appendix 10)
2. Building a thematic framework: developing codes and initial categories and constructing an index (appendix 11 nodes): the index should have a hierarchy of main and sub themes. Labelling or tagging data (appendix 12 with tags): linking raw data to the indexed codes and ordering them. Creating thematic charts: (appendix 13). Each theme and associated sub topics are plotted on a separate chart.
3. Developing descriptive and explanatory accounts: Data moves beyond original text and is interpreted in a more conceptual way (e.g. systems and processes becomes the “ceremonial order of the clinic”, attributes of EP can be reconceptualised as” EP as navigator.

Stage 1: This involves reading and re-reading of transcripts to become familiar with the data. Ritchie and Lewis (2003) in their analogy of conceptual scaffolding refer to this as foundation building. Already at this stage the researcher begins to identify recurring themes or topics. In order to aid this process a descriptive account (appendix 8, p222) was constructed to show the analysis process from raw data to initial codes.

Stage 2: Using NVivo 9.2 (QSR 2012) involves manually coding data, examining transcripts line by line and assigning highlighted text to a node. Once all transcripts are coded in this way a coding matrix or index is formed (appendix 11, p230). In NVivo 9.2 this matrix consists of nodes, (child and parent nodes; the equivalent of codes and sub codes). From these nodes themes can then be derived, which involves clustering similar nodes together as well as constantly refining nodes. This index is usually constructed of data allocated *a priori* codes; described by Bazeley (2007) as any concepts derived from the research question, for example “perceptions of partnership” and *in vivo* codes which are described as emic (Hollway and Freshwater 2007), and emerge from the data. Transcripts are then revisited and data tagged against the numerical index codes (appendix 12, p231). It is acknowledged that passages may be linked to more than one code and are multi-indexed (Ritchie and Lewis 2003). The final stage of building the

thematic framework is to construct a thematic chart for each of the themes and associated sub themes (appendix 13, p243).

The third stage of the framework process is the development of descriptive and explanatory accounts, which involves refining categories and classifying data to a higher level of abstraction. Analysis is carried out across cases, rather than within cases (Ritchie and Lewis 2003). At this stage typologies may be assigned (e.g. fully engaged, partially engaged, not engaged patients) to which all participants must be assigned. This will be further discussed in the results/discussion section (p126), but is also illustrated through the use of a mind map (appendix 14, p250).

## **5.20 Trustworthiness and Authenticity of Data**

As with elements of the research process discussed previously, (transcribing, use of software), there is also debate around the use of the methods employed to increase rigour (Lincoln and Guba 1985, Holloway and Wheeler 2010, Silverman 2005). This is partly derived from the application of positivist terms such as “reliability” and “generalisability” to the Interpretivist paradigm, which is at odds epistemologically.

Social Constructionism denies that knowledge is a direct perception of reality (Burr 1995), thus as reality is viewed through the eye of the beholder, constructionism argues that there is no such thing as an objective fact. Seeking replicability is therefore an artificial goal and does not account for context nor the interpretation of the original data (Ritchie and Lewis 2003, Rolfe 2006). Topping (2006) suggests a more conciliatory position which recognises that what is being represented is a perception of reality rather than an absolute truth, whilst Silverman (2005) argues that there is a place for quantitative approaches within qualitative data analysis, such as tabulations, which can increase the quality of the analysis.

Positivist terms have subsequently been replaced with those that are believed to have more resonance with qualitative research values such as confirmability, dependability, trustworthiness and credibility (Glaser and Strauss 1968, Lincoln and Guba 1985). However the usefulness of this approach is further debated by Rolfe (2006, p309) who asserts that

“the quality of the research cannot be assured by the rigorous application of a set of previously agreed strategies and procedures”

but is judged by the reader, through the subjective appraisal of the research report. However, Rolfe (2006) acknowledges that this judgement involves some skill on the part of the reader.

Despite the debate around rigour in qualitative research there would appear to be some consensus that different forms of triangulation can be adopted rather than over-reliance on one method, (Denzin and Lincoln 2000, Patton 2002, Rolfe 2006). Thus, in order to increase the rigour and transparency of the analysis process, several strategies were selected. These included field notes, member validation, peer review and reflexivity. These are discussed in turn and will be returned to in the results section (p102).

### **5.21 Field Notes**

Field notes are defined as a record of the observations of researchers in the field during observation or interview, (Holloway and Wheeler 2010). Silverman (2005) argues that field notes are not merely recordings of events but also the field worker's analysis of events and should reflect what the researcher sees and hears and how they are behaving and being treated. Field notes can be further categorised to observation notes, theoretical notes, methodological notes and personal notes, (Richardson 2000). For the purpose of this study a reflective diary incorporated theoretical, methodological and personal notes. Observation notes were incorporated into the interview and observation transcripts.

## **5.22 Respondent validation**

Member or respondent validation was planned to validate interpretation of participant's narratives (Lincoln and Guba 1985). This is contested as a means to establish credibility for several reasons. Firstly it is argued that ethically it may be too much to ask of the recipient who may be frail, have unburdened, or disclosed sensitive information and may not wish to revisit the event (Polit and Beck 2004, Koch 2006, Cooney 2011). Further Silverman (2005) suggests that although we can ask respondents to account for their actions, feedback cannot be taken as a direct validation of the researcher's inferences. A further issue of contention is the determination of which respondents to ask in order to seek validation of accounts. McConnel-Henry et al. (2011) question why some respondents are chosen over others and argue that researchers should be transparent in the processes used to determine this decision. This is further discussed in the results chapter (p102)) and in the limitations of the study (p126).

## **5.23 Peer review**

A third method to increase rigour of the research was planned through peer review and debriefing. Holloway and Freshwater (2007) describe this as the analysis of data by colleagues and comparison of findings to the researcher. It is purported that peer debriefing may detect bias or inappropriate subjectivity (Holloway and Wheeler 2010). However, an opposing view suggests that because of the principal researcher's familiarity with the data, interpretation by an external peer will be through a different, less familiar lens, thus affecting the interpretation (Morse 1994, Armstrong et al. 1997). Thus peer review will be included to enhance rigour and transparency in the research process (Dowling 2006, Jootun et al. 2009). This process is presented in the results section (p102).

## **5.24 Reflexivity**

Reflexivity in research can be viewed from several standpoints. Its primary purpose can be said to engage the researcher in a process of continuous self-appraisal and critique in order to allow the collected data to be free from contamination by the researcher's own biases and preconceptions, (Dowling 2006). This requires the researcher to operate at several levels during the observation and interview processes. Snape and Spencer's (2003) view that researchers both influence and are influenced by engaging in research is supported by the author. One way to illustrate this is through the use of field notes and a reflective log throughout the data collection and analysis process (Silverman 2005). A further method is the appointment of a critical friend (Morse and field 1996, Grix 2001). The author views her supervisors' roles as fulfilling that function and plans to deploy all of the other methods discussed to ensure rigour; reflexivity, respondent validation and peer review. A further method of ensuring transparency with regard to highlighting potential issues in the research process was through completion of the ethics application (QMU, 2010, WHO 2011, NHS Research Authority 2013).

## **5.25 Ethics**

Whilst one might argue that any research imposes ethical responsibilities on the researcher (Gray and Smith 2009), Silverman (2005) suggests that in research involving patients' narratives or exploring behaviours, the researcher's own values as well as their ethical responsibilities must be faced. He suggests the researcher should consider the ethical issues that lie in wait in gaining access to a group of participants. Miles and Huberman (1994) contend that ethical choices almost always involve trade-offs, balances and compromises amongst the pros and cons of carrying out research. They pose several considerations which the researcher should contemplate prior to embarking on a research project. These include the worthiness of the project, the costs, benefits and reciprocity, issues of harm and risk, honesty and trust, research integrity and quality, consent, confidentiality and advocacy and ownership and use of data.

Consideration of these issues led the author to ask several questions of the main ethical issues which would be confronted during conduction of the research. These were linked following Beauchamp and Childress, (2009) to moral principles of justice, respect for patient autonomy, beneficence and non-maleficence. Further, adopting Mason's (cited in Silverman 2005) questions relating to the purpose of the research and implications of the research may help to expose the researcher's values.

Whilst it is acknowledged that one aim of the Professional Doctorate is to develop skills in academic leadership and contribute to the profession of nursing, the purpose of the research is also to further explore issues that have arisen through evidence, experiential knowledge and personal study, which may in turn have implications for future practice. This then in part justifies the worthiness of the study as its purpose is to explore strategies used by young "expert patients" with cystic fibrosis and healthcare professionals to maintain and negotiate partnership. The ethical implications that were perceived to be pertinent are as follows:

Firstly, familiarity with staff and potentially some patients who are previously known to me in my former role may create bias (Hawthorne effect) or make staff feel uncomfortable during the consultation process. Secondly, raising sensitive issues might be perceived by patients as a threat to the therapeutic relationship. Thirdly, loss of confidentiality may result between patients and HCPs if data is shared between them and more widely through presentation of results and inappropriate storage of data. Further issues include gaining informed consent and process consent from patients and staff, observation of poor practice during a consultation and my competence to undertake the study. Strategies to address these issues are discussed in appendix 15 (p251, draft ethics applications section A6-1)

## **5.26 The Vulnerable Researcher**

Completing the application, participating in the research Ethics panel meeting and applying for Research and Development (R&D) and Caldicott Approval and a research passport have all been a very steep learning curve for me. Several issues have emerged through these processes which were unanticipated; these included time delays, navigating through the NHS Information Governance process and consideration of systems and processes within my institution, particularly with respect to equipment, encryption and storage of data.

Silverman (2005) contends that the very nature of qualitative research as inductive; meaning it may change direction, may result in the emergence of new and unexpected ethical dilemmas. As a neophyte researcher, perhaps then it is unrealistic to be able to anticipate all that lies in wait, (Pruitt and Privette 2001) as one doesn't know what one doesn't know.

An example of this relates to an omission in the Caldicott application of the intention to employ an external transcriber. This necessitated further planning to instigate systems which would safely allow transfer of encrypted data without compromising data protection, (Data protection Act 1988, NHS Scotland 2011) and required a further amendment to the Caldicott application. Remedial actions to the application and communication around this issue impacted on the timeline of the research.

Ballamingie and Johnson (2011) assert that the literature pertaining to ethics in research leans towards the participant as the vulnerable party in the research process. However they contend that the novice researcher can also be vulnerable and cite their experiences as doctoral researchers to evidence this. They cite issues of powerlessness as researchers, and a lack of willingness by participants to engage, as a result of poor



practices from previous researchers. (See also Clarke 2006, Mauthner 1997, Harden et al. 2000).

## **5.27 Access**

In terms of the population under study, young people with CF are an already highly researched group (Lowton 2006). They are relatively small in numbers, meaning they may be asked repeatedly to participate in studies. Furthermore as the science of CF continues to develop in terms of treatments and the search for a cure, (CF Trust 2011) researchers continually seek to recruit subjects to help advance future management. The ethical dilemma posed for this researcher is whether this research may add to the potential for research fatigue in these already over-researched subjects.

One of the purposes of an ethics committee is to consider the population under study, as well as determining that the application is robust, gives a sound rationale for the study and identifies the potential ethical issues and their management, (Johnson and Long in Gerrish and Lacey 2006). Multiple requests for ethics applications with this group may be identified as an issue, thus the researcher must be able to justify the study and ensure that their behaviour throughout the research process is exemplary (Miles and Huberman 1994). Hill (2011), a doctoral researcher, suggests that ethics committees' goal of protecting subjects from upset may be unrealistic at times, particularly when dealing with sensitive topic areas. She suggests that it might be unrealistic to expect a participant to disclose data of a particularly sensitive nature without some venting of emotion. Additionally she supports Bondi's (2005) work which suggests that emotion should be considered not as an object of study but as a medium which connects and necessarily immerses both the researcher and the researched. Feeling emotional and drained after a research encounter is not a unique phenomenon (Dickson-Swift et al. 2006). It is reported that researchers can feel exhausted and overwhelmed, especially when researching sensitive subjects (Gregory et al. 1997, McCosker et al. 2001). Additionally emotions of frustration and feelings of vulnerability

resonate strongly with this author in relation to navigation through the research ethics process. These feelings of frustration and vulnerability have perhaps been accentuated by a tightening up of information governance in the NHS in light of a series of high profile cases relating to insecure storage and transfer of personal patient data (McKinley 2011). The potential consequences of breach of guidelines such as The Data Protection Act (1998) and The NHS Scotland Code of Practice on Confidentiality (2003) can be up to £500,000 in fines, therefore it is hardly surprising that approval is not given lightly. All data must now be gathered on encrypted devices, locked whilst in transit and immediately downloaded onto a computer with the appropriate compatible software. This has necessarily involved more steps in the ethics process, such as Caldicott approval (NHS Scotland 2011) which adds to the time-line in the ethics approval process.

## **5.28 Summary**

This chapter has critically explored the design, methodology and methods proposed and implemented within this study. The first half of the chapter debated the proposed epistemological, theoretical and methodological perspectives. The design, while located in the qualitative, interpretative paradigm, is influenced by social constructionism and Symbolic Interactionism (SI), and a methodology of Descriptive Interpretivism. The second half of the chapter discussed the proposed methods of non-participant observation, and semi-structured interviews as well as sampling and recruitment strategies. Thereafter consideration was given to analysis of data, rigour and reflexivity. The chapter concluded with a discussion of ethical considerations and strategies were offered to address these issues.

## CHAPTER SIX: RESULTS

### 6.0 Introduction

The purpose of this chapter is to present the main themes of the research study in relation to the research thesis. Results will be presented, using the research questions as a framework. Findings will also be categorized into *a priori*, emergent and analytic themes. Silverman (2005) suggests that in writing up the findings the writer should make clear what the main messages are and must reflect these in the data that are presented.

He suggests there are at least three models which may underpin the macro structure of the thesis; the hypothetical model, the analytic story and the mystery story. The analytic story, (the chosen method here), is, he suggests, a more conversational way of writing and should highlight the main theoretical concepts (*partnership, interaction between expert patients and HCPs*), and discuss how the findings illuminate these concepts. Strauss and Corbin (1990) state that one must always consider the reader when conveying the key messages: each message must be accompanied by enough conceptual detail to help the reader makes sense of it. Hence the findings section reports the *process*: what happened as opposed to what was planned and draws on the field notes, as well as reporting my interpretations of the results.

In using this approach, this chapter is deliberately interwoven with process, reflection and findings in an attempt to tell a story which is representative of the whole experience (Mellor 2001, Woolcott 2002). Whilst findings are presented in the third person, in keeping with the convention for reflective practice (Jasper 2006), reflections on observations and in field notes are written in the first person.

Silverman (2005) proposes that the first stage in writing up results is scene setting. Thus, a descriptive account based on field notes is offered in order to set the context of the observation in the out-patient department (the clinic) and my role there. This is

followed by presentation of descriptive data related to the out-patient process of consultation. The analytical themes are considered in the discussion section.

## **6.1 Contextualising the clinic (field notes)**

In a “standard” out-patient clinic the usual procedure is for the patient to attend at reception where they are checked in then ushered to a waiting room, where they sit amongst a group of patients. During this time they may be called upon to be weighed, measured, or undergo blood tests or may simply be called into a consulting room by a nurse or doctor whereby a consultation takes place. Thereafter the patient leaves. Unlike a “standard” clinic, patients in the CF clinic do not wait in a communal waiting area but are ushered straight to a single room to ensure there is no opportunity for patients to meet in the communal area and potentially cross infect each other. Thus the clinic waiting area has the appearance of being empty, but the corridor sees a range of HCPs (consultant, registrar, nurse, physiotherapist, dietitian, pharmacist, pulmonary technician) waiting around to access the patients.

Clinics are organised according to colonization of micro-organisms; for example all patients colonised with pseudomonas would attend on a separate day from those without pseudomonas. There are currently three different clinics running to accommodate patients with different colonised micro-organisms.

HCPs move from room to room to see patients rather than occupying their own room. This ensures minimal patient traffic across the clinic; the aim being to minimise cross infection rates between rooms.

Each room has a check-list on the door on which the HCP marks their time “in” and “out” so that other staff can see which room is occupied by whom and which staff the patient still has to consult with.

The clinic area has six consultation rooms. Clinic visits occupy two slots per afternoon which are scheduled one hour and forty five minutes apart; thus a maximum of twelve patients are seen per afternoon. In between the first and second clinics rooms are disinfected (chairs desks, equipment), in an attempt to reduce cross-contamination between the first and second groups of patients.

Patients are seen at clinic at different intervals depending on the severity of their illness, (the sickest patients are usually seen four weekly, the healthiest annually, others three or six monthly). Other issues that affect attendance are admissions to the ward (some patients rarely attend clinic as they are in the ward so frequently), compliance with clinic attendance, and shared care; some patients attend two clinics which are in different geographical regions to reduce travel. The majority of the clinic population is under 35 years of age. Some bring parents with them to clinic who may or may not sit in with them on the consultation.

As CF is a lifelong condition, (CF Trust 2013) many of the patients have been attending the same clinic for years and are well known to the HCPs. Many are on first name terms with the team. The majority have a staged transition from the paediatric clinic between the ages of fourteen and sixteen and continue being seen until death or a move away from the area.

The Clinical Nurse Specialist (CNS) arrives early to ensure patients are directed to appropriate rooms and are not mixing with each other. Thereafter they are charged with coordinating the clinic which involves keeping an eye on the flow of traffic through the rooms to ensure patients are not waiting for long periods without a consultation, arranging follow up appointments, prescriptions, equipment and carrying out any treatments required on the day (such as central line flushes). CNS' also identify in advance of clinic what bloods are required from which patients and which grade of doctor patients should see (consultant or junior).

## **6.2 Researcher's role**

I attended the clinic in advance of the first slot and waited for the patients to arrive. During this time of waiting, on-going consent was sought to observe the consultation from the HCPs who were also waiting for patients.

Once the patient was allocated a room, I was either escorted to the room by the CNS and reintroduced to the patient, or invited to reintroduce myself. In both cases on-going consent was re-established to observe the clinic consultation. No patients or HCPs refused to consent to the process, (all parties had previously given written consent).

Once consent to stay was established, I, with permission, set up the audio recording equipment and took a seat in a corner of the room, in an attempt to minimise my presence there. Often I was not the only "extra" person in the room. As this was a teaching hospital there were frequently medical or nursing students present, who had also sought permission to "sit in" on clinics to learn more about CF; this was a common occurrence. Additionally, on two occasions patients were accompanied by a parent. Both consented verbally to the audiotape being played during the consultation and both also agreed to be interviewed alongside their child during clinic "dead space". Agreement was also given to use their data in reporting and dissemination of results. This verbal agreement was followed up with written consent at the end of the interview.

During the course of the clinic consultation I took written field notes in free hand (to back up the audiotapes in case of equipment failure) and also loosely completed a Calgary-Cambridge guide (Kurtz et al. 2005) for each of the individual consultations between an HCP and patient (appendix 3, p213).

### **6.3 Non-participant observation: reflections**

Despite attempting to assume the role of non-participant observer, this did not always feel possible. On some occasions HCPs would acknowledge my presence on entering the room and sometimes refer to my previous role in the unit. Sometimes they would try to make eye contact with me while talking to the patient, which made me feel they were addressing me rather than the patient. Another HCP asked if she had “passed” at the conclusion of the observation, which affirmed the possibility of a Hawthorne effect. On another occasion, the nurse, whilst performing a procedure, explained to me how “the needles had changed since my day” indicating that she was well aware of my presence there and was including me in her interaction with the patient.

On yet another occasion a patient cracked a joke which was aimed at all of us in the room and I found myself laughing with the other two people in the room. HCPs would sometimes make comment after a consultation, giving an opinion that may have been at odds with what was directly seen or heard (e.g. such as the truthfulness of a patient’s account) which perhaps might not have been shared with a researcher who was unknown to the team. All of these matters questioned my ability to be non-participant.

However, a patient who was interviewed at home following an observed consultation in the out-patient clinic, remarked that due to my previous connections with the unit, she expected that the clinic consultation may be different from normal (due to my presence there). In spite of this she was quite categorical in her assertion that my presence had made no perceived difference to the consultation episode, which was reassuring.

However it is recognised that this is only one account from one participant.

On two occasions the consultation took an unexpected turn. As an observer I felt very uncomfortable being party to an unexpected revelation by one patient. An offer to leave the room was however rejected by the participants.

This led me to return to the literature on the vulnerable researcher (p87) as I realised that in order to protect myself it would be important to debrief and seek support from supervisors. I also found myself wanting to rescue this particular individual and realised that this was not part of my remit, but highlights the tensions that neophyte may experience during the research process.

## **6.4 Interviews**

There were periods during clinic time where patients were left sitting unattended in the clinic room which allowed opportunistic interviews to take place on the research topic. These would then be interrupted by a continuous flow of personnel sequentially consulting with the patient; thus, returning to the research conversation was often challenging. Where the participant agreed to be followed up at home, this was less problematic as this gave time to reflect, refocus and prepare for the subsequent interview. However for participants who declined to do this, there was only one chance to “get it right”. All of the participants who preferred not to have a follow-up interview at home agreed to stay after the clinic to conclude the interview. However it was recognised that for some this was the end of a long day and thus I attempted to keep this discussion brief.

## **6.5 Results**

A total of 33 consultations were observed between 8 young people with CF (6 male, 2 female, aged 19-34) and up to 6 HCPs at a series of weekly out-patient clinics over a three month period. Two young people had a parent (1 male, 1 female) with them who accompanied them in the consultations (+1).

Of the 8 patients observed at clinic, 4 were interviewed within a few weeks of attendance at the clinic, whilst the other three (and the two parents) agreed to talk to me in the “dead time” in between consultations and after the clinic had finished.



A further 2 patients who were not observed at clinic were interviewed in their own home or in the ward during an in-patient stay.

All but one of the HCP's (n =11) were interviewed in their workplace within a few weeks of the clinic observation. Ten of these were interviewed individually and two personnel were interviewed together. One HCP who had been observed in one interaction on one occasion at clinic had subsequently left before an interview could take place. In total 23 interviews were carried out, (table 9).

Young people generally saw a minimum of four HCPs (usually physiotherapist, dietician, nurse and doctor) and up to six HCPs per clinic visit (previous four plus pharmacist and a psychologist, table 9, p99). In addition all patients had spirometry testing performed at each clinic and those who were also undergoing annual review tests, (pulmonary function and exercise testing, glucose tolerance test, bone scan) would have been at the hospital since the early morning. 33 consultations were observed (table 9).

**Table 9: Observed Consultations**

Participants	Dietitian	Psychologist	Dr	Physiotherapist	CNS	Pharmacist	Total consults
P1	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>6</b>
P2			<b>X</b>		<b>X</b>	<b>X</b>	<b>3</b>
P3 +1	<b>X</b>		<b>X</b>		<b>X</b>		<b>3</b>
P4	<b>X</b>		<b>X</b>	<b>X</b>	<b>X</b>		<b>4</b>
P5	<b>X</b>		<b>X</b>	<b>X</b>	<b>X</b>		<b>4</b>
P6	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>5</b>
P8 +1	<b>X</b>		<b>X</b>	<b>X</b>	<b>X</b>	<b>X</b>	<b>5</b>
P10 (pilot)			<b>X</b>	<b>X</b>	<b>X</b>		<b>3</b>
							<b>33</b>

p= patient, +1 = parent.

The witnessed consultations lasted in total between 60 and 121 minutes. On some occasions there was no pharmacist available for clinic. The psychologist tended to see patients out with the clinic setting but would attend if requested. On the occasions where there are no witnessed consultations with the dietitian or physiotherapist, (table 9, p2,p3), this is due to my absence rather than that of the HCP.

An analysis of average time each HCP spent with each patient was attempted but the results should be viewed with caution. Findings may be more credible when the HCP was the same person, (physiotherapist, pharmacist and dietician) than with the doctors and nurses who were each witnessed in consultation less often. This is because there were more of them and they rotated at clinic every three weeks rather than attending weekly. Furthermore the individualised nature of patient problems at any given time may have necessitated more input from one HCP on that occasion than on a subsequent or previous time.

**Table 10: Average consultation time per HCP**

HCP	Average consultation time	Range-comments	No. of witnessed consults
Pharmacist	7 minutes	(3-12)	5
Dietitian	16 minutes	(10-25)	6
Physiotherapist	16 minutes	(9-23)	7
Nurse Specialist (x3)	14 minutes	(7-22)	8
Dr 1	8 minutes	(6-10)	3
Dr 2	16 minutes	(16)	1
Dr 3	25 minutes	(17-33)	2
Dr 4	11 minutes	(9-13)	2

There were periods when patients were sitting alone in their rooms seeing no-one; this has been defined as “dead time”. Dead time ranged from 13-30 minutes across the witnessed clinic visits or, expressed as a percentage, accounted for 17-36% of the patients total clinic time, (median 29%).

Educational status data was collected as it was hypothesised that participants’ level of education may impact on perceptions of partnership and ability to negotiate and challenge in interactions with HCPs.

**Table 11: Details of all study participants**

<b>Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Education</b>	<b>Observed</b>	<b>Interviewed</b>	<b>Place</b>
P1	28	M	SS	<b>X</b>	<b>X</b>	OP/Home
P2	34	M	SS	<b>X</b>	<b>X</b>	OP/Home
P3	19	M	SS	<b>X</b>	<b>X</b>	OP
P4	22	M	SS	<b>X</b>	<b>X</b>	OP
P5	31	M	SS	<b>X</b>	<b>X</b>	OP
P6	19	F	SS	<b>X</b>	<b>X</b>	OP/Ward
P7	26	F	SS		<b>X</b>	Home
P8	21	F	FE	<b>X</b>	<b>X</b>	OP/Home
P9	20	F	SS		<b>X</b>	Ward
P10 (pilot)	19	M	SS	<b>X</b>	<b>X</b>	OP
Parent 1		M	SS	<b>X</b>	<b>X</b>	OP
Parent 2		F	SS	<b>X</b>	<b>X</b>	OP
HCP 1		M		<b>X</b>	<b>X</b>	OP/Office
HCP 2		M		<b>X</b>	<b>X</b>	OP/ "
HCP 3		F		<b>X</b>	<b>X</b>	OP/ "
HCP 4		F		<b>X</b>	<b>X</b>	OP/ "
HCP 5		F		<b>X</b>	<b>X</b>	OP/ "
HCP 6		F		<b>X</b>	<b>X</b>	OP/ "
HCP 7		F		<b>X</b>	<b>X</b>	OP/ "

HCP 8		F		<b>X</b>	<b>X</b>	OP/ "
HCP 9		F		<b>X</b>	<b>X</b>	OP/ "
HCP 10		M		<b>X</b>	<b>X</b>	OP/ "
HCP 11		F		<b>X</b>	<b>X</b>	OP/ "
HCP 12		M		<b>X</b>	-	OP

### **Key**

SS: Secondary school, FE: Further Education, OP: Out Patients, P:Patient

HCP: Healthcare Professional

## **6.6 Analysis of the consultation process using the Calgary-Cambridge Guide**

Each interaction between patient and HCP was observed using the Calgary-Cambridge guide (Kurtz et al. 2005, appendix 3, p 213). The form served as a means to observe the opening and closing of the interaction, the communication styles used and to note biomedical and patient perspectives in the interaction. In all cases interactions were led by the HCPs. In some cases it was obvious through their interactions that patients and HCPs were well known to each other. In a few cases this was the first meeting between the two.

On three occasions patients had an accompanying partner or parent who sat in on the consultation. On the two occasions where a parent was present they interjected from time-to-time in the interaction between the HCP and the patient. The third occasion was the accompanying person's first time at clinic and of the three HCPs who saw the patient, only one acknowledged the presence of this person in the room. This person did not contribute at all to the conversation. Consultations varied in the amount of social chat that took place. Usually this took place at the beginning of the interview;

" I hear you got a new car?"

At other times consultations moved straight into biomedical mode;

“ Hello, how’s your chest today?”

As expected the majority of the interactions was biomedically focused and took the form of questions and answers. However, towards the close of each consultation all HCPs offered opportunities for patients to raise their own issues;

“Is there anything you want to ask me?”

Generally nurses and the psychologist adopted more holistic approaches. There was heavy emphasis by HCPs on compliance with physiotherapy and medicines but patients appeared to be very comfortable disclosing non-compliance with treatment. Patients retold the same stories several times to each of the HCPs. On one occasion a patient recounted their substantial drug history three times. HCPs expected patients to be able to chronologically recount details of symptoms and dates of tests and investigations

“when was your last bone scan?”

Patients expected HCPs to be up to date with recent events in their trajectory and to have read their notes before the consultation:

“When did you last have IV’s?”

“Did you know I was on orals and had a reaction?” (observation notes- Dr flicks through the notes and obviously can’t find what they’re looking for)

“Ah, ok, what happened?”

Patients saw between three and six HCPs at a clinic visit. This resulted in them having to make sense of multiple communications and instructions from many sources.

## **6.7 Analysis of qualitative data**

Data were analysed thematically as detailed in (chapter 5, p78) using "Framework"; a matrix-based analysis approach (Ritchie and Lewis 2003). All of the observations and interviews were audio recorded and transcribed verbatim. Transcripts were read and re-read to ensure familiarity with the data. Those audio-recordings that were transcribed by the assistant were listened to whilst regarding the printed transcripts to check for accuracy. The assistant had no insider knowledge of CF terminology thus some of the technical jargon in the transcripts was misinterpreted and had to be corrected.

All data were manually coded using NVivo 9.2 (QSR 2011). Transcripts were examined line by line and highlighted text assigned to a node until a coding matrix was formed, (appendix 11, p230). This process was aided by construction of a descriptive account (appendix 10, p226) which was designed to show how the analysis moves from raw data to codes and themes. The coding matrix was then refined through the process of clustering similar nodes and refining existing nodes, (for example "negotiation" moved from a distinct theme (parent node) to become an "enabler to partnership" (child node), and "social" and "biomedical" constructions of illness were merged to form "constructions of illness". The matrix was then numbered; thus "experiences of partnership" became an overarching theme (1.0) with a code of "barriers to partnership" (1.1) and sub codes such as "parental surveillance" (1.1.1) and "power dynamics" (1.1.6, appendix 12, p231).

Transcripts were then revisited and raw data tagged to the numerical codes to form a thematic chart (appendix 13, p243).

Mind maps were then constructed to create a model to bring the narrative together (appendices 14, 19, p250, p290). The final stage of Framework; the development of descriptive and explanatory accounts is considered in the discussion section (chapter 7, p126).

## **6.8 Credibility and trustworthiness of the data**

As discussed in chapter three, several strategies were employed to increase the trustworthiness of the data, these are discussed in turn.

## **6.9 Peer review**

To ensure rigour an uncoded transcript was sent to two independent researchers who had agreed to be peer reviewers. They independently scrutinised the transcript then reviewed the thematic and coding charts in relation to one sub theme; barriers to partnership. Both peers found high levels of agreement with me in relation to the thematic analysis, (appendix 17, p288).

## **6.10 Respondent validation**

Respondent validation was undertaken by one patient in the sample. An uncoded verbatim transcript was sent to this recipient to check for accuracy of the data. Secondly an initial version of the coding from this transcript was sent and the recipient was invited to comment on my interpretation of the data (appendix 19, p290). Interpretation was said to be accurate and well understood. Further respondent validation was undertaken by one of the CNS' who provided clarity and helped confirm concepts during data analysis through telephone conversations.

## **6.11 Reflexivity**

Personal reflection on why these persons were chosen to undertake this task was logged in a reflective diary. With regard to the choice of CNS, this was purely down to chance, to whoever was available at the end of the telephone at a given time. I do recognise however that the choice of patient may have been less random. I recognised

that here was someone who was very experienced as an expert patient, who was highly engaged and articulate and who was willing to be seen at home, which meant more uninterrupted time than if an interview was held during a clinic visit.

However I also acknowledged that this recipient was not atypical within the small sample of ten and thus I would have been comfortable asking any of the group to give feedback on the analysis process. It is acknowledged however that this may have resulted in a different interpretation of events in line with the ontological and epistemological stances taken in the research.

### **6.12 Thematic results**

Three major themes emerged from the data, (table 12, p104) these were; experiences of partnership, attributes of the expert patient and constructions of illness. These themes are threaded throughout the research questions. Within these themes a number of sub themes were identified: for example from the first theme - experiences of partnership- five sub themes emerged; the ceremonial order of the clinic, enablers and barriers to partnership, emotion work and relationships.

Some overlap in reporting of findings is inevitable; for example perceptions of partnership (Q1), makes reference to terms such as respect and negotiation, which may also be perceived as outcomes (Q2), or enablers or barriers to partnership (Q3), or strategies (Q4).

Further analysis of the data allowed themes to be classified into *a priori* and analytical themes and emergent and analytical themes (tables 13,14, Appendices 20 & 21 ).

Word constraints prevent presentation and discussion of all the results in the narrative form. Those that have been included were chosen either because they are strongly representative or because they appear to be novel and add new knowledge (e.g. HCPs as too soft) and are outlined in table 12.



**Table 12: Results presented in narrative form**

	<b>Major Theme 1</b>	<b>Major Theme 2</b>	<b>Major Theme 3</b>
	<b>Experiences of partnership</b>	<b>Attributes of the Expert Patient</b>	<b>Constructions of illness</b>
<b>concepts</b>	Attributes & Beliefs:(e.g. power, respect)	Attributes, definitions (e.g. experience v's expertise)	Impact of CF and coping
<b>Subthemes</b>	<b>1.Negotiation</b> (HCPs as too soft)	<b>1. Expert patient as navigator</b> (self, systems, processes)	<b>1 Normalcy</b> (minimization, embeddedness of treatment burden)
	<b>2. Relationship building and influencing factors</b> (building bridges to achieve adherence, competing agendas, preferred personalities)	<b>2. Emotion work</b> (voicing cues and concerns, agendas, prioritizing)	
	<b>3.Enablers to partnership</b> (power of the nurses, HCP' acceptance of patients' experiential knowledge,		
	<b>4. Barriers to partnership</b> (systems and processes; the ceremonial order of the clinic, life stage, parental surveillance, lack of trust)		

## Theme 1: Experiences of partnership

Both Groups (expert patients and HCPs) appear to believe that in the main the relationship they have with each other is a partnership. The context of the partnership may be perceived as unique due to the duration of the partnership and stability of the team. Some of the patients have been attending the same clinic for up to twenty years.

*"I think my personal feeling is that CF encourages partnerships more than a lot of other teams. I think it is because we have relationships with people over many years and I think that we see that those relationships develop" HCP 9.*

*"I think it is a partnership, in fact even more so that with other patient groups because we know them really well" HCP 3.*

The importance of the duration of the relationship was also made by patients

*"Aye, it's just annoying when they change, 'cos they know you, trying to think who's still here, who knows me. (lists names), half them I don't know, you see different people" P5.*

### 6.13 Defining partnership

Partnerships were seen by some as hard to define,

*That's hard... it feels like it should be a relationship 'cos you see them that often but what other words could you use instead of partnership- difficulty defining partnership P1.*

whereas others had a clearer definition of what partnership meant to them, which included shared knowledge.

*"I do believe it is a partnership. I 've got easy access to them, to each specialist, not only do they teach me new things, I'm quite good at teaching them" P8.*

Definitions were not universal and in some instances-particularly in relation to the HCPs-partnership was not thought to be a relationship of equals.

*"So partnerships are not necessarily partnerships of equals um, the John Lewis Partnership, not everyone is an equal partner in that, the financial bit at the end*

*is equitable so partnership is a politically correct word and I think it means people work with patients which I think we've always done" HCP1.*

*"I think with some patients it's a partnership, I think with other patients its more prescribing to them. In saying this is what we want you to do and they do it. I think they do that without much thought of why, they think, they're the docs, the nurses, the professionals and they tell us what to do and they like it like that" HCP 6.*

Definitions of partnership would often make reference to the nature of the relationship between the "partners" (see also enablers and barriers, Q3); however not all relationships were defined as partnerships. Some members of the team (nurses, psychologist) were perceived to be partners by the young people, whereas others (medical staff) were sometimes not viewed as such.

*"It is a partnership – there has been times that I've felt that I've not been listened to as well as well as I should be – I wouldn't say the nurses but more the consultants" P7.*

*"Depends who you're working with"  
"So who?"  
"The nurses" P1.*

## **6.14 Power**

Power in the partnership was seen by both parties as a shifting dynamic, (see also Q3). Sometimes expert patients saw power situated with the HCPs- particularly the medical staff:

*"Doctors are away up here, really high up, dietitians are in the middle, well actually they're probably below the CF nurses, so the nurses are in the middle, so they communicate everything you say to the doctors, whereas the dietitians and the physios won't really say anything, they'll keep it to themselves" p9.*

However power could also shift according to context

*"Yeah, so they've got the power (in the ward) but obviously when you're at home you've got the power. You decide what you do", P1.*

However sometimes HCPs perceived power to be held by the young experts

*"I think they are quite an intimidating group if you talk to other people who don't deal with CF who deal with them on the ward, I mean the poor house officers and even the registrars get kind of.....the patient will say to them, I'm not seeing you, you know nothing, I want the consultant and they can be really quite difficult to even very senior doctors so that can be difficult for doctors and somebody in training particularly" HCP 3.*

Medical staff in particular expressed a perception that within the team, the nurses were most powerful and were very skilled at using power covertly or overtly in order to get what they wanted; for themselves or for the patient

*"nurses are skilled so mostly they will play a game and they might speak beforehand or they will feed appropriate lines so they know what response they are going to get so nurses are cleverly skilled in that" HCP1.*

This was confirmed by the nurses

*Laughs- "well it's not often they don't" [do what we want] (laughs)*

R. So you're making that decision and communicating that in such a way?

*"Yeah it's how you put it to them" (laughs) HCP4.*

### **6.15 Attributes of partnership**

When probed, attributes of partnership were perceived as respect for autonomy, negotiation (see Q2), and the nature of the relationship between the two partners, (see Q3). Patients perceived that HCP's holistic knowledge of them was also essential for partnership (see Q3).

### **6.16 Respect:**

*"I think there's definitely something there about respect, obviously you respect them but I think they respect me as well, my opinion, dinnae always think they're right and happy to acknowledge that they don't always get it right, so is a respect there as well for the patient" P7.*

*"Id like to think it is, we very much try to respect their wishes and to listen to what they're saying about impact of CF on their life". HCP6.*

*"What else can they do, [laughs], cannae make you take it, it's like when they put me on colomycin, I never done it, I telt them I wasnae taking it, so they scrubbed me off it 'cos they kent I wasnae taking it" P4.*

## **6.17 Negotiation**

Negotiation emerged strongly as an important outcome of partnership, but also as an attribute of and enabler to partnership. For patients negotiation might mean an outcome of a reduction in their treatment burden, which is often considerable, or a delay in admission, or reduced length of hospital stay. For HCPs negotiation might result in an outcome of increased treatment adherence. Thus a sense of "meeting in the middle" might be seen as an outcome of partnership. For HCPs this required negotiating a hierarchy of priorities and bargaining as to that which required most attention.

*"It is negotiated 'cos you.. instead of 7 days a week on the nebulizer you do 5 cos you're doing sports and my doctor says you dinnae need to do .. so stuff like that is negotiated" P3.*

*"So they're maybe not doing 4 treatments and you think well there's no way we're going to get them to do all of that so you think what would be the single thing that we could perhaps agree to try and move forward on and try and pick out the most important thing that might make a difference" HCP2.*

In all but two cases negotiation was perceived to be happening between patients and HCPs (however despite reporting non-negotiation, negotiation *was* observed during the consultation in one of these two cases).

*"There's no' real negotiating, take the doctor, if you say I'm not feeling great , they'll suggest a plan, but they never really say, how does that sound, or how do you feel about that? Could we tweak it in any way or..." P1.*

Another patient who appeared to be the most passive of all the participants did not wish negotiation

*"I'm happier for them to make those decisions" P6.*

However from discussions with the team it was clear that despite having a perception of others taking control of decision making, this patient often agreed a plan then deviated from it, thus renegotiation would inevitably take place.

### **6.18 HCPs as too soft (see also Q4)**

A common finding from the HCPs with regards to negotiation was their perception of being “too soft”.

*“I’ve learned through bitter experience that fierceness gets you nowhere, (laughs) and so I do engage reverse gear quite positively... and the reality is that IV’s are very rarely urgent so it’s quite commonly possible to get the patient to start IV’s the following week” HCP2.*

*(field notes-this is quite a change from when I was in practice- I do remember fierceness and an unwillingness to bend- I wonder if that’s the benefit of experience, and of failure to get what was asked for?, seems to have mellowed).*

*“Sometimes what I’ve noticed is that the doctor will say to somebody, you should come in for 2 weeks of IVs and that person bursts into tears and immediately the doctor backtracks and says and gives them orals and then assuming that they are not giving optimal care and I know that is an area that I’ve been involved in where I’ve had to say, you need to hold your nerve” HCP9.*

*“More so than in other areas, patients get away with refusing things”. HCP 11.*

This was confirmed by patients

*“but I can think of other people with CF and I’m thinking I would’nae let you away with that, but no’ me” P8.*

*(field notes) patient in clinic recounts in earlier days how he would engineer an admission to the ward just to be with pals, and they would disappear in the evenings and “muck about”, no real sanctions imposed P5.*

Thus HCPs choose their battles carefully in negotiation

*“Oh definitely you’ve got to pick your battles” HCP2.*

## 6.19 Relationship building

At the heart of this “back tracking” and softly-softly approach is a perceived need by HCPs to “keep patients on board”, sometimes at the expense of a more rigorous approach to treatment. This is seen as part of relationship building in the partnership,

*“And it’s all about keeping them on board and sometimes you just have to accept that they just won’t do it and they are deteriorating and you’ll have seen that and at some point it’s accepting that and just being supportive” HCP7.*

*“You have to be flexible as much as you can be, and I think we are. I think we are very... to the extent that it can be abused at times- d’you know- the patients know we’re flexible” HCP4.*

*“I think that is a criticism of all chronic health teams (being too soft) and seeing from outside particularly, I think that would be the case, that we give in a lot but I think sometimes in order to progress things, you have to give a bit to gain more in the end” HCP3.*

This can be trying for the HCPs, thus frustration can also be perceived as an outcome of partnership

*“E.g. in a general clinic if the patient didn’t turn up twice in a row they would be discharged, and that’s the difference with CF they’re never gonna be discharged, we’re always gonna see them and I think some of them come along when they need something, (laughs), sometimes they don’t understand we just want to catch up with them and see how things are going, they’ll only turn up to clinic or the ward if they’re not well or they need something. So there are allowances made which I think is good but it can be frustrating” HCP 11.*

*(field notes- so what sanctions can the HCPs actually use? how can you set ground rules if you’re not prepared to abide by them- must pursue)*

## 6.20 Building bridges to achieve adherence to treatment

Keeping patients on board is commonly driven by HCP’s agendas to improve and maintain adherence to treatment, which in CF is time consuming, increasingly technical

and at times overwhelming for patients. Thus an outcome of good partnership as perceived by HCPs is improved adherence to treatment. This is seen by HCPs and patients as the most challenging aspect to partnership as the same agendas may not always be agreed.

*"The softly-softly approach is much better for getting to the goal you want. I don't mind if the patient gets the feeling that they've run a little circle around me in the short term provided they get to the right place in the end. Laughs I'd rather they felt that it was like a little victory [laughs] than they felt they'd been brow beaten" HCP2.*

*"He lets me look at his sputum but he won't let anybody in. I don't take it personally – you have to find a way in to say, hi I'm here without aggravating them. Is that a partnership with the patient because I'm listening to them but they don't want me?" HCP 7.*

## **6.21 Competing priorities/agendas**

Agendas were not always the same for the patients as HCPs. Patients perceived a need to balance treatments with other competing priorities in their lives, thus unlike the HCPs concordance with therapy was not always at the top of their list.

*"Depends how motivated you are as a patient, but for me sometimes 'cos I find it hard to juggle everything, yeah so sometimes I do find their expectations are high" P1.*

*They understand there is an element of having to fit it in to your life- antibiotics etc, but I dunno how much they think about that? I mean could they think about themselves doing that? Oh I've got to do IV's but I've got to pick up the kids, so do they actually think how...? P7.*

For some patients CF and its management was seen as lower down the priorities list than other factors in their life.



*"Isn't CF, it's about having a life. I've got CF – I live with that but having a life is more important – life is short – you have got to have the experiences while you can and the last few years have been amazing – I've had the best years of my life" P9.*

*"Ah dinnae want to do it, I've been doing it for years and it gets boring", P3.  
(field notes- parent shaking head, obviously doesn't want to hear it!)*

This was frustrating for carers who, like the HCPs wanted CF and its treatment to be a priority.

*"....will not really speak about it much – he would just rather forget that he's got it and just comes to his appointments but that's what he has to do" +1.*

Whilst HCPs acknowledged competing agendas in their discussions;

*"The reasons patients tend not to take treatments are they're worried about the side effects, they really haven't got the time to do it and they don't actually see what the benefit is. So patients have good reasons not to go along with it and I think any member of the team who thinks patients go along with all the recommendations is probably quite naive" HCP 1.*

patients felt that this was not always evident.

*"The CF team are always gonna be...they want you to do physio' twice a day, 3 times a day. They've got high expectations and sometimes you wonder, do they actually think I've got a social life, I've got a job, I've got a family and I've got a house and I've got all these other things happening, but they want you to ,,, sometimes it feels like they just want you to focus on your CF, and that's all they see, and that's frustrating because it's like yeah, they just see you as a CF patient and that's it" P1.*

This tension was acknowledged by HCPs but the requirement for treatment adherence was viewed by them as necessary against a backdrop of deteriorating health;

*"That's difficult because sometimes you know that what you're asking them is almost too much to bear. Patient right now not coping, really unwell who feels like her QOL is zero which it is, but knows that if she doesn't do it, she's really*

*struggling. ...so yeh sometimes I think we ask too much but if you don't ask..." HCP10.*

Other outcomes of partnership included provision of a safe haven for patients (i.e. admission) when the burden of treatment became too much.

*"Important you feel that if things get on top of you and you are struggling at home, at the very least it'll be a safe place for you, ok?" HCP2 (observed).*

*"Aye they're really good, the CF nurses are really brilliant, I ken if I ever need them I can phone them up and if I need to come in, they'll get me a bed and I stay for 2 weeks" P4.*

However, admission was not always seen as a desirable option, as it usually meant patients had less control in the ward.

## **6.22 Enablers of partnership: Relationships between HCPs and expert patients; the power of the nurses**

By far the greatest enabler to partnership was the perceived nature of the relationship between the "partners". Both parties perceived that the people most significant in sustaining this relationship were the CF nurses. Patients perceived that they were usually the first point of contact, were more equal in terms of power bases (see Q1) than other members of the team and had holistic knowledge of them.

*"Aye they're really good, the CF nurses are really brilliant, I ken if I ever need them I can phone them up and if I need to come in, they'll get me a bed and I stay for 2 weeks" P4.*

*(field notes- is this just because of their position; i.e. first at the end of the phone or is there more to it?)*

*"Keep coming back to the nurses, they're better at helping diagnose, giving treatment, medication, they're more hands on, see more of the patients, deal with them more, see the environment you're in,... not treated like a number, come and flush my port so see where I live, who I live with, seeing the environment I live in, so they probably ... empathise maybe" P7.*

The HCPs also valued the nurses for their holistic knowledge of the patients and their co-ordinating role within the team.

*"The clinical nurse specialists have a depth and a breadth of relationship and a knowledge of the patient that is second to none and as a result, they are the cornerstone of almost everything in the service" HCP9.*

HCPs relied on the nurses to communicate and action this knowledge, which they perceived saved time in the consultation process. For some doctors this allowed them to focus more on biomedical issues.

*"I guess as a medic you go down the biomedical line 'cos that's what you see as your job. I was hoping that the nurses were doing both". HCP2*

However all of the HCPs felt that other strategies were in place to gain an holistic view of the patient, such as the team meeting before and after clinic, and their use of open questions at the end of the consultation (which was witnessed in nearly all cases).

*"Is there anything else you would like to discuss today?" HCP3.*

### **6.23 Acceptance of experiential knowledge**

A further enabler to partnership was HCP's acceptance of patients' experiential knowledge. Almost all of the patients felt that their experiential knowledge was recognised and respected.

*"Aye they go by what you say more than... we've got a rough idea of what's going on with us, Obviously they realise that we've had this since we were born, we've lived with it day to day for 30 years now, they understand" P5.*

For some HCP's this recognition came gradually and was part of their own experiential learning.

*"When I started this job I would look at the FEV1 and if it looked alright and they were saying that I've got a cough and I feel rubbish, I would think well the FEV's*

*fine, but now I would err much more on the side of listening to how they feel before I look at the spirometry, and use the tests as a supporting thing" HCP2.*

Carers also felt that their experiential knowledge should be recognised. Whilst this was usually perceived to be the case within the CF team, it was not always apparent with other HCPs and could be frustrating.

*"What I would say is, there should be an acceptance, which there never is that we know probably as much as them [GPs]" +1.*

## **6.24 Barriers to partnership**

Barriers to partnership included systems and processes, developmental stage, parental surveillance and lack of trust; particularly in relation to treatment compliance and power differences (see Q1). These are discussed sequentially.

## **6.25 Systems and processes**

This theme refers mainly to organisational barriers such as lack of resources out-of-hours, poor communication between team members and the structure of the clinic which is repetitive for patients and can be exhausting and time consuming.

*"Weekend staff, weekend care is horrendous (no CF team). That's one of the major barriers..... If I took unwell on a Saturday I would hang on till Monday because sometimes I feel it's pointless if there's no' a CF team there" P7.*

*"Not good is its time consuming, only 2 rooms have windows, at first I was quite claustrophobic, had to learn, get used to the wee confined space... I prefer not to go to clinic if I'm honest, I'd rather just keep in touch and ask the questions rather than sit about for 2 and a half hours when I've got nothing to say and you go over the same questions" P8.*

HCPs recognized the limitations of the clinic set up but had to balance this against their professional accountability and the need to gain a set of information for each patient which is fed into a national database.

*"But I think the doctors would argue that they have to cover the bases, ask the person in case there's something missing" HCP4.*

## **6.26 Impact of Life event/stage**

Adolescents, those who had recently transitioned from paediatric clinics, were often perceived by HCPs as particularly challenging "partners", with regard to relationship-building and also in relation to adherence to treatment.

*"Oh yeah. I learned a huge amount from the early transition clinics. There were patients staring at the floor, no eye contact, patients not saying anything at all during difficult transition clinics, with the paediatrician present refusing to speak. So that's the extreme end of the lack of partnership", HCP2.*

*"Dealing with teenagers, it's like rebelling or.. it's a big challenge" HCP10.*

Patients acknowledged that often this was the case, but with the passage of time and significant life events priorities changed somewhat.

*"No, I still get up to mischief like but I'm no always up to mischief, it was a gradual thing, I actually care about myself now, back then I wisna bothered, I was stupid, just wanted to have a good time while we were here" P5.*

*"I just decided, what are you doing? You're just screwing yourself over for the future. You wanna live, why don't you? So..."P9.*

## **6.27 Parental surveillance**

A further factor which impacted on the nature of the partnership and could be perceived as a barrier was parental surveillance. For the HCPs building a rapport could be difficult if a parent was unwilling to let go.

*"I know, we have a patient in his mid-20's and we've just realised that he doesn't want us to make any changes at the clinic 'cos his mum will ask him what the changes were and give him a row about it if we make a single change" HPC3.*

Young people were conscious of parents' need to be involved despite moving away from home

*"My mum wants to know what's going on but I just won't tell her" P9.*

*"In paed's it wasnae between me and the doctors it was between you (carer) and the doctors" P3 (field notes- parent is sitting in on the consultation, young person a bit truculent, obviously wants to get in and out as soon as possible, but parent has other ideas and has own agenda, things to raise)*

Parents acknowledged this difficulty in letting go but were frightened of the consequences of not intervening,

*"It's a huge transition for the parents, because you end up not knowing what's going on, and because of that, it impacts on what you're saying because you dunno what's going on, you've less knowledge on how to deal with what's happening" +1.*

*"I actually felt that way when she first came up here. So strange that they werenae asking me the questions, everything directed at her, took me a few months to get....I felt worthless" +2.*

## **6.28 Lack of Trust**

A further barrier to partnership was perceived as a lack of trust by HCPs. Whilst it was apparent that young people placed their trust in the HCPs (with a few exceptions), HCPs were less likely to trust patients' accounts of compliance with treatment. This could be evidenced through the constant checking at clinic by HCPs regarding compliance with treatment and by responses to the question of trust at follow up interviews.

*"A lack of trust yeah, yeah I think it's true that we don't trust them to take their medicine, that's completely true (laughs). Should we trust them to take their medicine? No we shouldn't trust them. I hope we can trust them to tell us they are or are not taking their medicines HCP2.*

*"I still probably err on the side of optimism but I've been stung, ...so sent him off and when I saw him he'd well we'd agreed that he was doing it 3x week and when i said that at the post clinic meeting, and psychologist picked up something different then he told the physio' something else, so I think maybe the people who have doubts have learned from experience". HCP 10.*

However some patients felt upset about this lack of trust;

*"But sometimes I get the whole- some doctors are like -so do you take your nebs. And sometimes I'll say don't tar me with the same brush 'cos I'm no' a liar. Just because there are other patients that don't do it, Doesnae mean we're all the same 'cos we're young and we want to go out. It offends me a wee bit, that's the only thing that I think is a bit unfair". P8.*

Generally when questioned young people appeared to be very honest about their lack of compliance (see also Q4),

*"Are you checking your blood sugars ever?"  
"No". P4.*

and in the main this was recognised by HCPs.

*"I don't think they try to be devious about it, most of them are up front, they're not all up front" HCP1.*

As well as being an enabler, relationships between the two parties were also perceived as a barrier to partnership, usually because of the approach that was taken in their interactions.

## 6.29 Relationships between HCPs and expert patients

*"It's funny because the nurses always seem to be the busiest, but do you know they always take the time, even if it's just 2 minutes, just to reassure you, or ...but the doctors just, they're like a whirlwind sometimes, come in fly round the room, leave" P1.*

Some patients specified a preference for a specific HCP.

*"More about personality. I'm more into somebody who's willing to sit down and have a chat with me than somebody who goes around, like I've got 100 patients to see so how fast can I do it... this, this and this ok, bye" P9.*

Whilst others were ambivalent.

*"No they're all the same to me, no preference" P8.*

## 6.30 The expert patient: attributes

There was no real consensus between the two groups as to the definition of the expert patient, although some commonalities in attributes were perceived, such as experiential knowledge of self, systems and treatments, engagement, monitoring, experimenting and forward planning. Patients were largely uncomfortable with the term "expert" and preferred the term "experienced".

*"Aye, 'cos its happened before, so you know" P4.*

HCPs were more sceptical about the term expert patient and whilst they acknowledged that there were expert patients they also suggested that there were also a number of patients who perceived themselves as experts who were not.

*"But to imagine expert patients, that word implies that they have put a lot of effort into understanding their disease and for a lot of people that doesn't apply. They've experienced their disease, they might do some superficial working, which is internet, but that's a hit or a miss, it's not guided" HCP1.*



HCPs suggested that some patients were also expert in navigating and manipulating systems to get what they wanted.

*"Yeah who's button to push, they know how it all works and how it works. They'll phone the CF nurses, I'm waiting to see an ortho' surgeon 'cos my knee's sore, can you speed it up? That's an extreme but it still happens" HCP5.*

*(field notes, dead-time conversation about how all the young lads would engineer admissions at the same time, then disappear from the ward in the evenings and muck about!)*

This manipulation also extended to avoiding the clinic and to picking and choosing who they wanted to see. Instead of attending clinic patients could self-refer by phoning the ward and could be seen there more quickly without going through the ritualized clinic system. This sometimes created problems for the CNS' who may have been available to see the patient but were unable to access a physician to prescribe medicines or examine the patient. This could result in long waits and logjams in the system. Further evidence of manipulation was by those patients deemed "intimidating", who refused to be seen by junior medical staff (see power, Q1).

### **6.31 Knowledge**

Knowledge of self was often associated with an "early warning system" whereby patients could recognise when an infection was "brewing". This was very individual, so for some an impending chest infection was detected by a slowing down of the bowels, rather than specific chest symptoms.

Knowledge of treatments was evidenced through observation of discussions at clinic of drugs, nebulisers and physiotherapy. Patients would often query dosages of drugs and their interactions.

*"Yeah, (forcibly), there are probably plenty people who would just say, tough just get on with it, but I think it's always worth querying" P2.*

### 6.32 Engagement

The previous quote also demonstrates the attribute of “engagement” which was agreed by both parties as being linked to the concept of the expert patient. It was clear that patients who were engaged came to the clinic with an agenda of the issues they wanted addressed.

*"If the nurse or dietitian comes in and says something like how are you today, I'll say, as soon as I can get it in to the conversation I'll say, I'm here to ask about my stomach, I would slip it in as soon as I get the opportunity" P7.*

### 6.33 Emotion work

This agenda was however not always openly voiced. Rather, patients used cues or waited to be asked. When asked why they did this as opposed to being more forceful, they appeared to be concerned with showing respect to the HCPs.

*"I could've told him that 10 minutes ago, but with these new people they've got to do it themselves" P5.  
(field notes- could see from body language and responses that he's following the orchestral dance of the consultation, why doesn't he just say what the problem is?)*

HCPs recognized that patients did not always openly voice their agendas.

*..."So if they therefore secretly want some antibiotics because they are going on holiday in 2 weeks time, well a) we probably know that's the case and would probably talk to them about that but if we don't know, they will give us an excuse to give an antibiotic rather than saying I am going on holiday and that's to avoid being disappointed by the b..... who says you don't need them" HCP1.*

It was also suggested that context may have something to do with unvoiced agendas. Thus patients coming to clinic for review are less likely to have an agenda than those who self-refer to the ward for a specific issue.

Sometimes this covert voicing of agendas appeared to have an emotional cost.

*"They all laugh at me, if I've got an opinion that I try to put across I will tell them but put it across in a funny sarcastic way. Rather than saying there's something in my stomach, I need Kleen prep, they don't take it in an offensive way 'cos I'm jokey about it" P7.*

*"Interrupts- they fish for them" (antibiotics).....when you go fishing you dunno if you're gonna catch anything, P8.*

Emotion work also included navigating through and making sense of many different sets of information from different members of the HC team.

*"What I struggle with right now is the different opinions that everybody gives; some person might say one thing and another person another and I take both on board, I try to do what they're telling me to do then I get into a pickle and I think..."P1.*

This involved selecting that perceived as important and discarding that perceived as unimportant.

*"I dismiss stuff, I know that sounds bad but some things I get told at clinic- I think well I'm no' skinny, I'm no underweight, so if she's saying to me try and do this or that-I think huh! Well I'll decide [laughs]" P7.*

Further attributes of the expert patient pertained to the amount of experimenting, monitoring and forward planning that took place in the day to day management of CF. Much of this was taken for granted and appeared embedded in daily routines, but involved forward planning for events such as holidays, chasing up results or prescriptions or covert or overt administration of medicines and monitoring of their effects.

### 6.34 Constructions of illness: embeddedness and normalcy

"Embeddedness", also extended to patients' perceived minimisation of the impact of the disease on daily life. On first discussion when asked about the impact of CF on day to day life, almost all patients viewed the effect of CF as not that significant. However when probed the range of treatments and burden of care was in all cases significant.

*"I'm just trying to think. To be honest, not very many treatments now that I'm looking after myself" P5.*

This patient however upon probing revealed that he required endoscopy and oesophageal banding monthly, and that he had substituted physiotherapy for exercise which occupied a significant part of his day. In addition he spent the first half hour of each day coughing and vomiting in order to clear his chest of secretions. He also mentioned after probing that regular interventions were required for his blocked gut.

In another situation it was not until almost the end of the interview that it emerged that the patient had Insulin Dependent Diabetes Mellitus. This patient was in poor health but appeared to voice her diabetes almost as an afterthought, despite the need for constant monitoring and insulin injections. This pattern of minimization was typical in all patients who were interviewed and was explained as follows:

*"See if I was well and I was diagnosed at maybe 13 or 14, I probably wouldn't have coped with it as well because I would probably feel slightly bitter because I had been well and now I'm not but because I've been diagnosed since I was 5 months so it's all I've ever known. To me, I don't think of other people not having to take tablets – it's just like a routine – it's strange." P8.*

Readjusting "normal" appeared to be part of the process of minimization

*"Were you short of breath coming up the stairs?"*

*"I dinnae take the stairs – I came up in the lift". P4.*

Thus lack of mobility in getting from A to B is "normalised" through the use of lifts for climbing stairs or driving instead of walking. Thus the problem of getting from A to B is overcome through the means used to get there and the problem ceases to be viewed as a problem.

### **6.35 Summary**

This chapter has presented the main findings of the study. These are identified thematically as; experiences of partnership, attributes of the expert patient and constructions of illness. The final stage in the framework process is to develop descriptive and explanatory accounts of the data (Ritchie and Lewis 2003).

From the main themes several important sub themes have emerged (see tables 12-14, p 107-109). These include building bridges to achieve adherence, the power of the nurses, the ceremonial order of the clinic, emotion work, continuation of the doctor-nurse game, the expert patient as navigator and normalcy. These are presented next in the discussion chapter and highlight the new knowledge emerging from this research. A pictorial representation of the findings of the research can be viewed in Fig 1, (appendix 13, p245). This may help the reader to view the research findings as a whole, as well as to examine the sub themes and view my journey through the "framework" approach.

In attempting to link presentation of the main themes and sub themes to the research questions it is recognised that some of the emergent themes (such as normalcy) appear not to be a good fit with the specific research questions. However, to omit them from the findings would be to omit a major emergent theme from the study. In defending preservation of this data, it appears fitting to cite Pruitt & Privette (2001) who advocate for researchers to 'expect the unexpected' and Mellor (2001, p465) who struggles with

“the untidy realities of research”.

Typologies were not assigned in this study as the three groups (patient, carers and HCPs) could not easily be assigned to one typology.

## **CHAPTER SEVEN: DISCUSSION**

### **7.0 Introduction**

This chapter aims to implement the last stage of the framework approach (Ritchie and Lewis 2003) through discussion and analysis of some of the *A priori* and emergent themes which have arisen from the study in order to address the research questions. Three central themes were identified from the findings: experiences of partnership, attributes of the expert patient and constructions of illness. Sub themes such as barriers and enablers to partnership are also presented here. Emergent and analytic themes (table 14, p.292) included the power of the nurses, building bridges to achieve adherence, the ceremonial order of the clinic, emotion work, HCPs as too soft, normalcy and the expert patient as navigator. Similar to the results section, not all identified concepts can be discussed due to the constraints of wordage thus, main themes linked to the research questions and those themes which can be described as novel are discussed here. Appendix 14 (p250) displays a mind map of all of the concepts identified.

Analysis of data is preceded by a discussion of the limitations of the study.

### **7.1 Limitations of the study**

Limitations of the study are deliberately placed at the beginning of the discussion chapter to ensure that all findings are discussed and analysed within the context of the limitations of the research design. This study was a cross-sectional study which comprised ten patients, two carers and twelve HCPs. Thus generalisations cannot be made to other contexts or groups. However the aim is not to generalise but perhaps to make some petit generalisations (Stake 1995) which may resonate with other CF practitioners and patients across other contexts. CF models of care are known to be similar across settings due to the constraints of cross infection and information

gathering discussed in the field notes, thus petite generalisations may be drawn across similar contexts.

The cross-sectional nature of the study means that I spent only a fraction of time observing the patient/HCP relationship in what has for many been a relationship spanning more than a decade. Consequently it is acknowledged that what was observed and heard was only a snapshot in an on-going long-term relationship. This may have resulted in some misconceptions. For example when the consultation launched straight into biomedical mode, one should not assume that the patient and HCP have not already had a social discussion on the phone or in the ward. Thus a snapshot cannot capture the on-going nature of the relationship between the two parties.

No parameters on severity of illness (e.g. FEV<sub>1</sub>, BMI) were recorded as this would have necessitated access to medical records and added another layer to the ethics application which was not deemed necessary. As the study seeks to explore partnership and social interaction, physiological data was not seen as essential to the study. However one might argue that if physical health does impact on social interaction at the clinic then this may be a potential limitation of the study.

A further limitation is my insider perspective which may have assisted in gaining access to privileged information not available to an outsider. This could be seen as a strength of the study as the insider's view may have elicited richer data than if viewed externally. However the reverse might be true; of staff behaving differently because of their prior knowledge of me. This tension has been highlighted through the field notes, through self-reflection and in accounts of conversations with patients about my role in order to ensure transparency.

It is recognised that convenience sampling may be a criticism of the recruitment process with the majority of patients self-selecting to the study through the posters or



leaflets available in the clinic. Others were approached by the nurse specialists. Subsequently results only reflect this sample group who may have been more keen to engage than other young people with CF. Whilst an attempt was made to attract a variety of patients across different social and cultural backgrounds, as well as patients who were seen as challenging as well as popular, regular attenders as well as non-attenders, recruitment has to operate in the real world of research and within the limitations of the research design. Recruiting non-attenders may have revealed a very different perception of partnership and perhaps this warrants further research.

Details on educational status were collected from patients as it was hypothesised that more highly educated patients would be more prepared to challenge professional authority. None of the participants had attended higher education, thus it might be argued that this group were not typical of the general population in terms of educational achievement. However it could also be argued that due to ill-health higher education was not chosen, not that patients were not academically capable; hence these findings should be viewed with caution. Previous research (Walters et al. 1993) found that the numbers of young people with CF with Advanced (A) levels was higher than those in the general population, thus findings in this study may simply be due to the small sample size.

The question of how to recruit "expert patients" remains unanswered at the end of this study as most of the patients would deny that they are experts; rather they would assert that they are experienced (p119). Criticism may therefore be accorded with regards to the inclusion and exclusion criteria for the participants in this study, but the literature is equally inconclusive as to what makes a patient an expert. Thus what may be required is a redefinition of terms.

The clinical team as outlined were very well established and had long durations of relationships with patients. Had the team been less established or experienced or stable then results may have been very different. However as already stated it is not the

140intention to generalise, only to comment on the case under scrutiny through the lens of the participants.

Despite these limitations, conversations with CF nurses at a recent international conference where I presented preliminary results brought forth many expressions of similarities across other CF clinics in the UK. Thus results appeared to resonate with HCPs more widely than just to the case under discussion.

A final limitation was the nature of the interviews during “dead time” at clinic. This was not ideal as often there were interruptions and patient consultations had to take priority. Thus the flow of the interview was lost until the next space in proceedings. However, failure to use this time may have resulted in no interview data; hence it was felt that some data was preferable to none. Other methodological approaches might have been considered in this group such as online diaries and blogs which may have negated the need for interviews with patients whose time may be limited.

## **7.2 Discussion: Experiences of partnership**

Both groups in this study perceived that for the most part the relationship is a partnership. However patients in particular struggled to define the term. In many of the patient discussions there was an absence of references to or implications of paternalism (although not exclusively). Instead terms such as respect for autonomy, shared decision-making and negotiation were offered by both patients and HCPs. One patient made reference to a commitment to the partnership; a feeling of obligation to turn up for clinic even though there were no particular health issues at the time. This patient was a known non-attender, but perhaps his attendance would be even more sporadic in a clinic where none of the staff were known to him.

Commitment has been described by Morse (1991) and was offered as a more appropriate term than caring in the nurse patient relationship. Commitment may be explained by the length and duration of the partnership in this study. Some of the relationships have been as long as 20 years duration and in many cases greater than 10 years. Whilst there have been some changes to the CF team within that time, the team

remains a stable one, with approximately two thirds of staff in the same post for at least 10 years. This may be unique to this case and may explain the level of commitment.

Duration of partnership allowed patients to come to know the HCPs consultation styles, and in doing so they could make choices about whom they preferred or insisted to see. Thus duration of the partnership may also be viewed as an enabler to partnership.

Many references were made by the HCPs to the duration of their relationships with the young people with CF. Whilst HCPs in this study acknowledged that there are other groups with chronic illness who may also have experienced longevity in their relationships with HCPs, it would appear that because of their young age, their vulnerability, their relatively small numbers and the rate of their physical decline, the relationship is perceived as a unique one unknown to other patient/HCP partnerships. However, findings are representative of only one case. Nonetheless it could be postulated that in other young people with a genetic condition, (for example, those with muscular dystrophy) that similar committed relationships with HCPs may be experienced. A search of the literature revealed little of note in this area, thus perhaps this warrants further research.

Commitment also seems to be a value held by the HCPs in the partnership, as evidenced by their tolerance and willingness to put up with things such as repeated non-attendance, which in other teams may result in patients being discharged (see page 111). Cahill (1996) described partnership as an agreed contract of commitment between parties. However in a later concept analysis Hook (2006) suggests an absence in the literature of signing up to commitment to partnerships. Despite the absence of formalised contracts of commitment in this study it would appear that commitment between parties still exists. Reasons for this are unclear but duration of the relationship and consequently attachment may be contributors. Thus it might be argued that within similar subcultures commitment or attachment may be an attribute of a longer term partnership, which might merit consideration in a revised model (Hook 2006).

Longevity of relationships was perceived by HCPs to assist the acquisition of extensive knowledge of patients' histories and personalities which served to facilitate the best way of "getting them to do things". Thus it appears the covert aim of good partnership at least for the HCPs was to encourage adherence with treatment. Despite earlier claims about the absence of paternalism it might be argued that the emphasis placed on "concordance" is paternalism in another format. Adherence to treatment is said to be approximately 30-50% in people with long term conditions (WHO 2003). It is also known that levels of adherence vary within and between CF treatments, (White et al. 2009, Abbot et al 2001).

The motivation to increase patients adherence was driven by HCPs' desire to improve health outcomes, however they recognised what they were asking of patients was sometimes too much. Patients' did not always feel that what was expected was realistic or achievable. This resonates with the literature (Bury 1988, Thorne 1993, Townsend et al. 2006). Townsend et al. (2006) argue that the constant need to improve symptom management (and thus increase adherence) is medically driven and not always prioritised by patients. Furthermore it has been found that HCPs may have unrealistic expectations of what constitutes optimal adherence (Raynor et al. 2001). A recent study corroborates this proposition. van der Vegte et al. (2013) asked 18 HCPs to adopt ritualistic adherence behaviours over a four week period in an attempt to mimic the demands placed on people with CF to adhere to treatments. Results showed that despite being motivated to participate, recipients found adherence very difficult to achieve despite expecting this of their patients. Given that this experiment was conducted over a month, it might be expected that adherence would be even lower if the participants were suffering from a long-term condition (Playle and Keeley 1998). Reasons for non-adherence to treatment in the literature are given as: forgetting, opposing priorities, complexity of regimens, failing to provide enough information about medicines and side-effects (Modi and Quittner (2006, Ovretveit 2012). Ovretveit (2012) contends that non or miss-adherence in relation to medication is one of the most

serious omissions which impacts on quality and waste in healthcare in the United Kingdom (UK).

Lindesay et al. (2011) in their integrative review of self-management in adolescents found that factors influencing medicines adherence included, age (although the evidence base is mixed), perceptions of illness and parental involvement. Whilst no firm conclusions can be drawn with regards to adherence in this study, it would appear that parental surveillance, age and developmental stage may have been an influence as evidenced by patients' reflections. Further, life events and biography appeared to impact on adherence in this study. Several patients commented on the impact that significant life events made on their attitude to their disease management, which served as a "wake up" call. Whilst others suggested that a change in attitude was simply the result of growing up. Abbot et al. (2001) found that adherence to treatment was also linked to optimistic and hopeful coping strategies. Furthermore Abbott et al. (2001) contend that there is some evidence that increased adherence to therapies is linked to faster disease progression and re-emergence of drug resistant organisms.

At a recent conference presentation (Abbot 2013) it was acknowledged that life events and developmental stage may also impact on adherence and coping and this warranted further research. The new knowledge gained in this study in relation to this topic may add to the body of knowledge but also warrants further exploration.

Given the perceived cost and impact of non-adherence to treatment perhaps then it is small wonder that HCPs place so much emphasis on this concept. However it is suggested that adherence needs to be explored in the context of patients' agendas, priorities and perceptions of what is realistic, (p113).

The term "partnership" was viewed with some cynicism by one HCP who saw it (and the use of the word empowerment) as politically correct terms. Whilst it is recognised that this is a minority viewpoint, the HCP had many years of experience of working with this group. This HCP viewed partnership as working with patients; "something we've always done" but felt that the term had been politicised. This HCP recognized that the

vast majority of patients are alone for 99% of the time, with HCPs only having a marginal input, thus patients have to be autonomous (Coulter 1999). This is in keeping with literature on self-management and the expert patient which asserts that the invisible, bottom up approach of illness work which was dominant until the late 90s has been reconfigured to present a top-down approach driven by policy, (Wilson 2001, May 2006, Rogers 2009) and is evidenced by the emergent use of the term “partnership” (and more recently co-production) in the amount of grey literature published in recent years (Wanless 2002, (DoH 2004, 2006, SE 2007, LTCAS 2008, NES 2009, LTCC 2010, DH 2010, SG 2010b, 2012a, Wallace et al. 2012).

Partnership was not always perceived to be equal in this study. HCPs acknowledged that equality was not always appropriate, especially when the patient knew little about a concept; such as lung transplant. Then it was agreed that it was more appropriate for HCPs to adopt a more paternalistic approach. Not all patients wanted equality and were happy for HCPs to take decisions on their behalf. This is consistent with previous literature (Waterworth and Luker 1990, Lawton 2003) and is a reminder that a “one-size fits all” approach to partnership is to be treated with caution.

Contrary to much of the literature around power in partnership (Henderson 2003, Gabe et al. 2004, Coyne 2007a, 2007b), there was no consensus across HCPs and patients as to the dominance of HCPs in the partnership. There was however consensus *within* groups, with patients perceiving that HCPs were more powerful, particularly the medical staff, which is in keeping with the literature (Strong 1979, Tuckett et al.1985, Pilnick and Dingwall 2012, Bensing and Verhaak 2012).

HCPs perceived that some patients were very powerful and indeed at times could be intimidating. This was evidenced by some by their insistence of who should review them at clinic and as in-patients, their intolerance of junior medical or nursing staff, and their refusal of treatments. This finding challenges the dominance of HCPs as holding the power balance in the patient/professional relationship (Strong 1979, Thorne 1993, Wilson 2007, Rogers 2009) but is consistent with literature that suggests that expert

patients pose a threat to professionals' sense of integrity, resulting in a culture of defensiveness, (Thorne et al. 2000, Henderson 2003, Shaw and Baker 2004, Wilson et al. 2006, Coyne 2006, Wilson 2007). It is acknowledged that within this study patient participants are of a younger age group than those in other cited studies. This group it is argued have grown up in a consumerist society and are perhaps less threatened in challenging HCPs than were their preceding generations (Lee and Lin 2010). Conceivably then the balance of power may be shifting.

Usually a refusal to accept treatment was based on patients' previous knowledge of systems and processes, such as the correct time to measure blood levels post-antibiotics, or the correct way to flush a central line or administer intravenous drugs, thus deviance from this or maladministration was not tolerated. Perhaps this is not surprising given the experiential knowledge which patients with chronic illness accrue over time. This knowledge extends to technical knowledge (Peterson 2006, Macdonald and Greggans 2010, Alderson et al. 2006), and many of the tasks listed above are often carried out by junior medical staff who may not have the same specialist knowledge. Thorne et al. (2000) describe a patient's experience whereby they report that despite repeated questioning of treatment, professionals insisted on continuing with therapy until the patient suffered irreversible renal damage.

As this group has been exposed to HCPs for most of their lives, perhaps the frequency and duration of those interactions, their life long experience and socialisation of health and systems have reduced their capacity to be daunted by them. However HCPs stressed that sometimes patients refusal to have treatments was as a result of fear of the unknown, or lack of knowledge and resolution involved working out ways of reducing, fear and "meeting in the middle" through negotiation (page 109) and education.

Context appeared to be important in power dynamics with the recognition that at home, patients perceived they held more power than in the ward setting, where they were more dependent on staff than at home and perceived they had little control. This

finding is supported by previous literature (Coyne 2006, Corlett and Twycross 2006a, MacDonald 2009), which suggests that power is often relinquished upon entry to health settings. However, recent literature also supports that even at home people feel uncomfortable when HCPs enter their homes, as evidenced by their feelings of being scrutinised in their own homes (Stoddart and Bugge (2012). This was not apparent within the case, but perhaps this was because there was no direct line of questioning around scrutiny. Rather, home visiting was perceived by both groups to be a way to see the person in their own context; which allowed HCPs to gauge not just the medical condition of CF but other aspects of their lives too.

Patients perceived a hierarchy of power between individual members of the HC team. Usually the doctor was perceived as the most powerful, with nurses, physiotherapists and dietitians lower down the hierarchy but equal to each other. This may be explained by several factors: historic traditions of medical hierarchy, (Davies 1995) and the amount of time personnel spend with patients. Usually patients see less of the doctor than other members of the team. Moreover, it may be explained by the amount of social interaction of a non-medical nature that takes place within these interactions, as nurses, the physiotherapist and the psychologist were more likely to be involved with patients outside the hospital setting and more likely to explore psychosocial issues. This was acknowledged by some doctors in this study, who saw this aspect of communication as part of the nurses role, leaving them to focus on symptom control and management. This role discrimination was perceived by the nurses to be driven by a widening job description for the CF fellow resulting in them having less time to see patients with CF. Thus nurse specialists were increasingly seeing and assessing patients and consequently spending more time with them. This finding was not universal however, with one member of the HCPs indicating that it was everyone's job to assess patients holistically, not just the nurses.

Interestingly, this HCP usually took longer in their consultations than other members of the team. This finding shares similarities with McIntosh and Runciman's (2008) qualitative study which concludes from their findings that development of partnerships



takes time and is resource intensive due to the complex web of relationships and the knowledge involved. This may create tensions when balanced against preserving the ceremonial order of the clinic to ensure patients are seen within their allocated time slots. Patients' described the importance of HCPs' having awareness of their social identities and of sharing of themselves and perhaps this practice facilitates a perception of equality between parties.

Most HCPs in the team perceived that the nurse specialists were the most powerful members of the team. This was claimed by the nurses themselves as well as medical staff and other members of the HCPs. Nurses appeared to be very skilled at advocating for their patients and sometimes did this covertly as well as overtly. Medical staff appeared to be well aware of the continuation of the doctor-nurse game (Stein 1967 p110) and voiced this openly. Stein's original theory that predominantly male doctors were being covertly guided by apparently compliant female nurses was revisited in the 1990s and found that in the face of power equalisation and the professionalisation of nursing, nurses were being more overt in making demands of medical staff (Stein et al. 1990). However, despite this finding, literature still supports continuation of the game (Reeves et al. 2008b, Holyoake, 2011). Reeves et al. (2008b, p1) suggest that the game will continue unless;

“the carefully negotiated historical territory of doctor-nurse relations and the pillars of professional autonomy and responsibility are transitioned from professionally anchored care to collaborative care.”

The authors suggest that the irony of the current game is that both parties find themselves on the “same side of the fence”. This would certainly seem to be the case in this study as the team appeared to be and described themselves as cohesive. However, despite the seniority of nurses and doctors in this study in terms of grade and experience, there appeared to be some continuation of the doctor-nurse game. Furthermore both parties appeared to acknowledge with humour that this was

happening, with one HCP commenting just how skilled nurses were at playing the game, such as “feeding appropriate lines”. Nurses reflected on the tactics they used to get what they wanted, including the methods they used to present requests to medical staff.

Reasons for the continuation of the game are unclear but perhaps these nurses who were socialised into the profession in the 1980’s are still bound by some of the historic traditions of the doctor-nurse relationship. Nonetheless nurse specialists also reflected on how their clinical experience has made them more assertive; willing to give opinions and not be “walked over” by the medical staff. They recognised however, that ultimately the power with prescribing and patient accountability lay with the medical staff. Currently none of the nurse specialists in this study are engaged in supplementary prescribing or advanced assessment or nurse-led clinics. This is at odds with some of their peers in other CF units. It is not suggested that having the power to prescribe would have an impact on game-playing, but may be a factor worth further exploration in terms of nursing autonomy.

Nurses described meeting with patients before the ward round and prompting them about questions they might ask the doctor. This may be an attempt to promote advocacy and empower patients (MacDonald 2006, Hanks 2008,) through the process of the game. Advocacy was also raised by the nurses in terms of patients’ agendas and their reluctance to voice them, (see also cues and concerns p50 ). Thus nurses would act as a go-between. This theme of “nurse as broker” shall be discussed further in enablers and barriers to partnership and will include an analysis of the advanced practice role of the nurse (p154).

### **7.3 Outcomes of partnership**

Whilst both parties recognised that negotiation was a successful outcome of partnership, a novel, unexpected finding from within the study was the perceptions by HCPs of being too soft in the partnership. This view was also expressed by some of the patients. Several potential explanations are offered to support this finding.

Firstly, the unique relationship developed between HCPs and people with CF referred to earlier, which is long term and stable, may support increased empathy in the HCPs. Perhaps knowing about the progressive nature of the disease makes HCPs more inclined to make allowances for breaking unwritten rules such as non-attendance at clinic, circumventing attendance at clinic by attending the ward, turning up out with agreed times or not adhering to negotiated treatment plans. A further explanation was suggested by a new member of the HC team, who felt the degree of rule bending within the case would not be tolerated in other groups (p110, HCP 11). This was rationalised as knowing that no matter what they did this group would never be discharged, meaning that they could get away with more than other patients. The effects of this are notable on resources, and have knock- on effects for other departments such as radiography, when for example patients are booked in for scans and procedures as part of their out-patient visits. Further, when patients do not attend clinic there can be more staff than patients present which results in a lot of “hanging around and frustration” (excerpt from field notes).

A further explanation for HCPs perceived leniency may be accounted for by the developmental stage of patients (Pai and Ostendorf 2011, Lindesay et al. 2011). Most of the HCPs expressed the challenges inherent in building rapport with young adolescents, who it is argued have not all developed formal operations of cognitive development (Piaget 1964) and are unable to engage in forward planning and hypothesising the outcomes of different actions. Thus they may be chaotic and disorganized with regards to self-management. This may also be explained by recent work that suggests changes

in brain structure continue into early adulthood and may impact on cognition processes such as executive function (Blakemore and Choudhury 2006). Further it can be argued that some adolescents are still developing communication and social skills towards the establishment of an identity (Bee and Boyd 2010) thus, this time of transition coupled with engagement with a new healthcare team can be challenging for all.

Bilton (2013) a physician with many years of experience of working with adolescents with CF suggests strategies to develop meaningful partnerships should consider the importance of setting ground rules, particularly in CF transition clinics when adult CF teams first meet with adolescent patients. She suggests they help create a culture of honesty and trust and asserts that ground rules must be agreed within the team as well as between patients and the team. This she suggests ensures that there are no in-groups and out-groups within the team and discourages patients from playing team members off against each other.

Skirbeck (2009) and Skirbeck et al. (2011) note that trust is rarely discussed in the physician-patient relationship, and only done so when it is close to breaking down. Whilst in this study HCPs (and one parent) talked about the development of ground rules and contracts it is not clear whether this has practice has been instigated. Further, should these be developed it is also not clear what sanctions if any would be imposed should contracts be broken.

Outcomes of negotiation included changes in treatment decisions such as instigation of oral antibiotics instead of intravenous treatments (IVs) which patients could self-manage at home more easily than if treated with IVs. This has resource implications as oral antibiotics are less costly, incur no in-patient costs, and may reduce the risk of cross infection during hospitalisation. Perhaps more importantly however home treatments (including IVs) may give patients a greater sense of control as they can manage this in their home environment with less disruption. A recent Cochrane Review (Balaguer and di Dios 2012) found no differences in clinical outcomes with home versus in-patient administered IVs. Although those at home reported higher levels of fatigue,

this may be balanced against the disruption of being an in-patient and the risk of cross-infection.

Whilst negotiation could result in frustration for HCPs, the more experienced team members acknowledged that over time they have developed strategies such as the noting the value of time, “adopting reverse gear” and acknowledging that treatments rarely have to happen immediately, thus there is always scope for negotiation which was witnessed frequently within consultations at the clinic. This has congruence with Stoddart and Bugge (2012) who refer to the key categories within negotiation as “experience” and “investment”. “The softly-softly approach” (p109) as cited by several HCPs infers investment in the relationship. HCPs appeared to accept this and “played the long game”; choosing which battles to pick and described a strategy of “gentle persuasion”. This strategy was usually borne out through experiential knowledge of what worked and did not work (p114) and was part of the relationship building designed to increase trust and thus increase adherence in the long term. However, it is not known if this strategy works. Haller et al. (2008, p 448) contend that there are no studies available which examine the outcomes of health beliefs on the consultation despite

“the apparent current trend of patient- centred care”.

Other properties of negotiation cited by Stoddart and Bugge (2012) are power and control (discussed on see page 133), and navigation and socio cultural considerations. Navigation is discussed on page 160. Sociocultural considerations have not been specifically addressed in this study but were discussed in limitations of the study (p126).

Despite the apparent willingness to challenge HCPs, patients often appeared to make demands covertly through the use of cues and concerns rather than directly stating their preferences. This is in keeping with literature from the 80s (Tuckett et al. 1985) and continues to be perpetuated to the present day, (Stevenson et al. 2000, Barry et al.

2000, Levinson 2000, Salmon et al. 2004, olde Hartman and van Ravesteijn 2008, Eide et al 2011).

Reasons for this lack of directness are still unclear, but it is postulated that power differences, (Wilson et al.2006, Coyne 2008), the setting, (Strong 1979, Gabe et al. 2004), the model of consultation (Strong 1979, Moore and Kirk 2010, Fischer and Ereaut et al. 2012) and the fact that not all patients want to lead the consultation (Entwistle et al. 2004, 2006, 2008b) perpetuate this practice.

Covert expression of cues and concerns raises the concept of emotional labour as an outcome of partnership. (Hoschild 1983, p7) describes this as

“the induction or suppression of feeling in order to sustain an outward appearance that produces in others a sense of being cared for in a convivial, safe place’.

This definition fits with the concept of emotional labour in healthcare and particularly in relation to nursing (Smith 1992, Bolton 2000). It is less fitting however when the concept is applied to patients, but emotion work could still be acknowledged as applicable to this group. In this study patients’ described behaviours such as “fishing for antibiotics” and making requests “in a jokey way” (p122). The first request is made through the use of cues and concerns (Hilde Eide et al. 2011) which imply that the patient’s chest condition is worsening but they do not directly ask for medication. Whilst the latter description does imply a direct request, it is requested in such a way as to appear to be non-demanding.

When HCPs and patients were asked why patients did not make direct requests, patients often made reference to giving doctors their place or showing respect. HCPs in contrast, suggested patients perceived power differences may have accounted for this practice. This was supported in some patients’ accounts of their perceived hierarchies of power (p106) and links to the literature (Tuckett et al. 1985).

Barrett et al. (2005) in a practice development evaluation study involving clinicians listening to patients evaluation of their care, found that often patients appeared to present a response that was desirable to them. Underneath the joking and having fun was a sense that the patient was scared, raising issues of the need to probe further and the constraints to achieving this; usually time and workload.

Within this study there were observed examples of probing which resulted in a much longer consultation than planned and a resultant referral to another professional which indeed impacted on time, workload and maintaining the order of the clinic. On another occasion (with a different HCP) a lack of attendance to cues was observed on one occasion and it was noted that this was a very short consultation. Whilst no conclusions can be drawn from these two examples, this finding is consistent with the wider literature surrounding the patient consultation, (Levinson et al. 2000, Barry et al. 2000). Contrary to Levinson et al. (2000) attendance to cues and concerns witnessed in this study usually resulted in longer consultations and in the second example described above, the consultation was one of the shortest witnessed. It is recognised that patient populations vary within the study and the wider literature. Perhaps the complex nature of CF and its associated complications and complex treatments means that attendance to cues and concerns may add to time and workload.

Morgan and Krone (2001) suggest socialisation of non-emotionality within the doctor-patient relationship is driven by the need to be perceived as professionals. Further, they assert that the power to manage emotions impacts on patients and so exerts the status quo of the bureaucratic format of the interaction. Thus, emotional labour as a construct within the patient/HCP interaction appears to be applicable to patients as well as HCPs.

Emotional labour also expressed by patients with regard to trying to cope with the multiple communications and reported variations in advice between HCPs. Wilson (2007) describes this as having the ability to navigate within a system dominated by medical and bureaucratic discourses. Navigation may also extend to the "rules of the frame" defined by Goffman (1959) as context (the clinic) and the situated roles and

rules, which are the domain of HCPs rather than patients. Wuest and Stern (1990) refer to this concept as “learning the rules” in order to develop expertise and found that helpful attitudes of HCPs assisted the development of partnership. Success in navigation results in the reward of respect and a relationship with HCPs (Wilson 2007), which Pattison (2001, cited Wilson 2007) suggests is tokenism.

Findings in this study suggest that emotional labour also occurs in patients as a result of HCPs lack of trust in them (p121). Thorne et al. (2000) refer to this perceived lack of trust as entering the consultation “preparing to do battle” and would appear to contradict the notion of partnership as one of mutual respect and trust (Gallant et al. 2002, Hook 2006). This concept is further discussed on page 145 under attitudinal barriers to partnership (Q3).

Emotional labour was also evident in HCPs accounts by their acknowledgement that the demands they make of young people with regards to treatment may be too much. They recognise however that the alternative is probably further deterioration in health. Additionally emotional labour in HCPs was expressed as a consequence of dealing with deteriorating patients who are themselves struggling to cope. This finding is not unexpected given the nature of the disease and the young age of the patient population in this study and is consistent with literature on emotion work in nursing people in pain and the terminally ill (Smith 1992). However Timmons and Tanner (2004) suggest that work that is emotionally charged should not always be associated with negatives and may result in high levels of job satisfaction.

Smith (2007) warns that there is a danger of muddying the waters in relation to the terminology around emotional labour, which has been blurred across two dimensions: that of work which involves an emotional element, rather than the specific strategies required to regulate self-emotion and the picture that presents to others. Feelings of frustration, anger and disbelief during interactions were acknowledged by both parties at interview, but rarely were these emotions expressed within the interaction suggesting that regulation of emotion was indeed taking place. As discussed in the next



section, this reserve continued to preserve the bureaucratic format of the clinic as identified by Strong (1979).

Strategies to deal with emotion work were discussed by some of the HCPs and included peer support from within the team and more formal support from the psychologist. This addresses HCPs needs but it is less clear what strategies are available to assist patients. Whilst there is also formal psychology input available for patients, perhaps what is also required are strategies that assist the empowerment of patients to feel free to ask for what they want in an equitable setting without fear of offending or misinterpretation that direct request or challenge is disrespectful. This may call for an alternative model of consultation from that which is currently used (Lewin et al. 2001, Gabe et al. 2004, Fischer and Ereaut 2012).

The presence of the bureaucratic format (Strong 1979) continues to exist in this study. At all times during non-participant observations both groups behaved with respect for the other person, and presented a public front of politeness to each other: that of frontstage behaviour, (Goffman 1959). However outside of the consultation backstage behaviour was observed and presented by both groups. In a few cases comment was made by patients as to the length of time taken to illicit information from them, but rather than take over and lead the interaction, they continued to follow the orchestral dance (Strong 1979, Fischer and Ereaut 2012) of the consultation through the ritual of questions and answers.

HCPs backstage behaviour was usually presented as conversations with each other regarding supplementary information around a patient's background, or the expression of disbelief between colleagues at a patient's level of adherence to treatment, yet this was rarely challenged directly in the consultation, confirming adherence to situated roles (Goffman 1975). HCPs justified this as playing the long game (p110), trying to foster a culture where patients felt comfortable disclosing non-adherence to treatment

and choosing which battles to pick. This is construed as an analytical theme of “building bridges to achieve adherence” and links back to the debate on paternalism (p131).

Discussion with some of the older patients in the sample revealed that significant events in their life such as the death of a friend or sibling or the birth of a child subsequently influenced attitudes to healthcare beliefs and behaviours. These events were interpreted as a sign that change was required and sometimes resulted in realignment of old priorities. Thus having a good time at the expense of treatment regimes, was re-evaluated to prioritise health over social events (p116). This finding contrasts with research that suggests that increases in adverse life events may have a negative effect on adherence (Leserman et al. 2008). Abbot (2013) suggests that this is an under-researched area that is ripe for further investigation.

## **7.4 Barriers to partnership**

Barriers and enablers to partnership (section 7.4, p145), were classified as either organisational or attitudinal.

### **7.4.1 Organisational barriers**

Organisational barriers identified in the study included lack of resources (time, medical personnel) and the “ceremonial order of the clinic” which has a biomedical focus, is repetitive for patients and is exhausting and time consuming. Patients reported; feeling claustrophobic when left in rooms on their own and being bored due to “dead” periods when they are left unattended between members of the HC team. They also report being subject to answering the same questions repeatedly; a practice which I observed regularly (p115).

The model of interaction in the clinic is largely justified on two grounds: the strict rules governing segregation to reduce cross infection which accounts for the isolation in rooms and secondly, the need to comply with the UKCF Registry database which

requires input of certain data after each patient visit. HCPs also cite accountability as a reason for the use of a repetitious biomedical model approach at clinic. Lack of direct questioning they assert, may mean something is missed for which they may later be accountable; a finding consistent with the literature (Horne et al. 2005). All parties recognise the frustrations inherent in this model and HCPs' report having tried other approaches; such as seeing patients in pairs to reduce the amount of contact time each patient needs to spend with professionals. However this approach was discarded as not always of value to the second HCP in the room, as they find themselves listening to information which is not relevant to their particular area.

Whilst it might be argued that *all* patient information is relevant in order to deliver holistic care, a system that uses two personnel in a consultation instead of one may be at odds with an NHS system that is already stretched and striving to the mantra of greater efficiency and effectiveness (DH 2010).

Similar to Strong's (1979) earlier findings, the consultations were physician-led, but in contrast to other literature (Tuckett et al. 1985), there was clear evidence of negotiation within the consultations in this study. Further, perhaps due to some of the advanced communication skills witnessed in consultations, interactions were situationally-dependent (Lee and Lin 2010), thus where patients had few issues consultations were shorter, where patients did express concerns, great efforts were made to attend to these through further discussion, referral to psychology or other measures. This often resulted in even longer stays at clinic for patients and a backlog of HCPs still waiting to see the patient within the allocated time before the next set of patients arrived and is at odds with literature (Levinson et al. 2000) suggesting that attendance to patients concerns saves time.

Thus, analogous with Gabe et al. (2004) it appears that in this study it may be the *setting* that is not conducive to holistic approaches rather than a lack of attendance to cues and concerns. This contention was echoed by the nurse specialists who reported that the majority of their work took place out with the clinic (at home and in the ward) and that these settings were more conducive than the clinic to holistic approaches to

care. However it is suggested that the group of patients the nurses are referencing are those with more severe disease and constitute less than half of the total clinic population. For others with milder CF who do not require admission or complicated home therapies, the clinic may be the only place that interaction between the two groups takes place. Discussion with a nurse specialist revealed that this group constitutes up to 50% of the total numbers. Thus, if it is being argued that the setting is inappropriate for holistic care, then this group may never receive it.

HCPs recognise that this setting may not always be appropriate to discuss some issues in depth and stated that they offered additional appointments or telephone appointments should patients want to discuss issues further. This may impact further on resources and may mean additional disruption for patients. The fact that patients are already finding ways around avoiding the ceremonial order of the clinic implies that it may be time for change (Fischer and Ereaut 2012).

When asked to consider alternative models of consultation, patients expressed a preference for the model similar to the experience of seeing one's GP – where the approach might be

“What can I do for you today?”

This approach focuses on the patient issue, thus is patient-centred, (Charles et al. 1997, 1999, 2000, Mead and Bower 2000a,b, Lovell et al. 2011), gets to the heart of the matter quickly and would avoid the repetitive questions which patients find wearing. This approach, whilst welcomed by some of HCPs as a possible alternative was rejected by others. Reasons for this are related to rigour and context. Patients usually go to their GP with a problem, which it is argued is different from the CF clinic where they are being reviewed without necessarily having any specific problems. Thus it is deemed essential to repeat the baseline questions each time to have comparable measurements. Further it is argued by some HCPs that the strength of repetition

results in a more comprehensive picture of the patient who does not necessarily give the same answer to the same questions being asked by more than one person.

It is suggested that there is a tension here between what patients want and what professionals fear will be missed.

The suggestion above also implies that patients cannot be trusted to decide what is important nor skilled enough to detect changes in conditions that would be picked up by HCPs despite a lifetime of experience and has congruence with Thorne et al. (2000) that this is down to entrenched values of HCPs. However, inherent in the GP model is an expectation that patients will take responsibility for illuminating those issues of central importance. Wirst et al. (2006, p.123) contend that;

*"the limitation of models of patient involvement is not—as is sometimes assumed—the potential difference between professional expertise and lay expertise, but rather the deep seated ethical and legal differences between professional and lay patterns of accountability".*

Wirst et al. (2006) suggest that in order to move towards new models of involvement there may need to be an increasing emphasis on patients' rights and responsibilities (such as being unable to sue if they exert rights to decision making) and consequently a decreasing emphasis on physician accountability.

Perhaps reassertion of each person's roles, responsibilities and expectations of the other would go some way to facilitate the piloting of such a model.

#### **7.4.2 Attitudinal barriers**

Attitudinal barriers to partnership included lack of trust, relationships between patients and HCPs, competing agendas, personalities, power, (page 109) and not being listened to. Parental supervision and developmental stage may also be barriers to partnership, (page 116).

#### **7.4.2.1 Lack of trust**

Lack of trust by HCPs was identified in relation to patients' accounts of their adherence to treatment. This lack of trust was expressed despite an observation that patients appeared to be very open with HCPs about their non-adherence and an assertion by HCPs that this openness was precisely the type of environment they hoped to nurture; where patients felt able to be truthful even if it contrasted with physicians' advice. Trust in the physician-patient relationship is often represented through patients experiences of care which are determined through the interactions between the two parties (Thorne et al. 2000, Lowton and Ballard 2006, Calnan and Rowe 2008). Thorne (1988) asserts that medical distrust of patients in her study was perceived by participants (patients) to be as a result of deeply entrenched values and behaviours which were manifest in the physician patient interaction.

Calnan and Rowe (2008) suggest that trust in post-modern societies is conditional, must be earned and is no longer based on status or deference to accredited expertise. Thus it follows that if trust is assumed to be an essential element of partnership (Hook 2006, Lowton and Ballard 2006), then it should be mutual. Explanations for lack of trust by HCPs were explained by their previous experiences of being "taken in" by patients who gave different accounts to different members of staff with regard to their level of adherence. The discrepancy in reporting is then detected at the team meeting following clinic. Whilst this was not witnessed in practice, it is recognised that I was not present at every clinic. However it was also suggested by one of the HCPs that perhaps the discrepant accounts are the ones that are remembered and they may in fact be in the minority. This HCP also speculated;

"whether any of us are getting the truth about how much drug is being taken".

In a critical realist view of compliance Wilson (2001) claims that the power to

label a patient non-compliant rests with the professional and indeed healthcare professionals are legitimised by both society and law as the definers of what constitutes appropriate treatment and therapy (Playle & Keeley 1998).

The previous point is perhaps illustrated by an account from a patient that deterioration in their condition was immediately assumed to be as a result of non-compliance. The same patient also commented that they didn't always trust the HCPs choice of treatment but that the nature of the relationship i.e. a dependent one, meant they were not always in a position to challenge this.

Skirbeck et al. (2011) conducted video observations and interviews with patients and physicians to explore trust in the consultation process. Findings revealed that trust was given implicitly to physicians by patients, but that trust was never absolute. This was evidenced through patients continually testing their physicians. Mandates of trust varied from limited to open mandates. Open mandates were linked to more knowledge of the patient and more complex patients. Alexander et al. (2011) suggest that repeated exposure between physician and patient over time through the consultation process can result in the development of trusting relationships which in turn are said to influence patient activation (and thus perhaps adherence).

Trust in the Skirbeck et al. study was only examined from the patient perspective and all patients in this sample were aged over 50 which differs from the case under scrutiny. Nevertheless some similarities exist between what was observed in the study and Skirbeck et al. (2011), that of patients' implicit testing of HCPs. This is further explored in relation to the concept of the expert patient as navigator (p160).

Trust is viewed as an essential concept within a partnership (Gallant et al 2002, Hook 2006). Thorne and Robinson's (1989) early work on trust describes a trajectory across the patient journey from "naïve trust" in the early years to "guarded alliance" as the patient becomes more experienced, develops expertise and consequently reconstructs the level of trust in the HCP. Guarded alliance could aptly describe what was witnessed

by both parties in this study as it would appear that neither party trusts the other completely.

Thorne et al. (2000) assert that what is required in relation to trust is a paradigm shift by HCPs of their values, expectations and behaviours, from a perspective of “acceptance” rather than “re-education a point is echoed by Dribben and Lean (2003) who assert that understanding the role of trust within the patient-physician consultation offers potential for better healthcare delivery.

This shift to acceptance may then further encourage the desired culture of honesty re non-adherence that was expressed by HCPs in this study and can be used as a basis on which to further develop trust.

#### **7.4.2.2 Relationships**

Relationships between HCPs and patients may be perceived as both a barrier and enabler to partnership. Some patients expressed preference as to whom they wanted to see at clinic whilst others expressed no clear preference. It was clear from backstage behaviour from HCPs that some patients were more popular than others (Stockwell 1972, Russell et al. 2003). Wilson (2007) refers to these as “ideal” and “heart-sink” patients. Unlike Wilson’s (2007) study there was no direct line of questioning regarding the ideal patient. However observations and field notes revealed that popular patients appeared to share commonalities with those in Wilson’s (2007) study of cheerfulness, giving positive feedback and appearing to embrace life despite their condition. These patients were not necessarily the most compliant patients-unlike those in Wilson’s (2007) study. Similarities from this study did appear to exist however in relation to heart-sink patients who were often sad, depressed or complaining. This was evidenced through the back stage behaviour of HCPs and it is acknowledged that this information may have been only gleaned as a result of my insider position through previous history of working with the team.



#### **7.4.2.3 Not being listened to**

Whilst the data from this theme emerged mostly from the patient group, there was acknowledgement from one or two HCPs that sometimes they didn't listen to patients. There are similarities in this theme with that of lack of trust. However they have been coded separately as lack of trust was usually in relation to perceived non-adherence, whereas not listening covered other topic areas such as timing of blood tests, efficacy of treatments and repetition of previously tried and tested interventions despite protestations. This resulted in several strategies from patients such as; outright refusal, agreeing to try, agreeing to try but deliberately deciding not to and using alternative remedies covertly. Patients narratives from the wider literature explain the use of these strategies as being informed by their personal, intuitive and experiential knowledge (Coulter 2002, Thorne et al. 2000, Fox 2005, 2008, Tyreman 2005a, Wilson 2007). Wilson (2007) categorised expert patients into four groups: covert and overt challengers and covert and overt accepters. Thus the participant in this study who covertly used alternative remedies would be classified as a "covert accepter"; someone who on the surface adopted a passive style but who accessed remedies covertly without the knowledge of the HCPs. In critiquing this typology it is asserted that patients may switch between typologies depending on contextual and other factors. For example the patient described above would openly challenge other aspects of care, whilst covertly taking remedies. Thus it can be postulated that other factors such as context, parental, peer and healthcare support and life story (Sawyer et al. 2007, Lindsay et al. 2011) may impact on such behaviours.

#### **7.4.2.4 Competing agendas and priorities**

This theme is discussed in relation to the biomedical versus social priorities given to each of the parties in the consultation and links to the theme of constructions of illness. As described previously much of the discussion at clinic was of a biomedical nature, especially that between patients and doctors. Other HCPs were more inclined to engage

in social chat referring to recent events in patients lives or interests which indicated personal knowing as well as disease related (empirical) knowledge (Carper 1978). Whilst patients recognized that HCPs had sympathies with and respect for competing events in their lives, they felt on the whole that HCPs' focus was on CF which was sometimes at odds with their own priorities. These priorities included work, family, having a good time, spending time with peers and "just living" in general. This aligns closely with previous literature (Bury 1991, Thorne and Paterson 1998, Abbot et al. 1996, Blue-bond-Langer 1996, Lowton and Gabe 2003, Koch et al. 2004, Badlan 2006, Charmaz 2006, Townsend et al. 2006, Taylor et al. 2008, Williams et al. 2009) which revealed that social roles, maintenance of identity and a "normal" life were prioritised over symptom control: a view often at odds with those of HCPs.

## **7.5 Enablers to partnership**

### **7.5.1 Relationships: The power of the nurses**

Almost unanimously all parties within the study attested to the unique role of the nurse specialists within the team as salient, knowledge brokers, negotiators, mediators, confidantes, co-ordinators, and as powerful forces in the team. Whilst there was also recognition of others' worth in the team, data attesting to the nurses strengths was repeated by HCPs and patients within the case with regularity. They were perceived to have a holistic knowledge of patients and HCPs (particularly consultants) relied on them to communicate and action this knowledge, which saved time in the consultation process and resulted in a perception by consultants that they could focus more on biomedical issues.

Whilst these accounts serve to evidence and strengthen the value of nursing, there may be a danger that assuming that it is the nurse's role to attend to the holistic component of care may aid the polarisation of biomedical and holistic approaches between the nursing and medical professions. In a post-modern consumerist era which calls for

healthcare to be more patient centred (Mead and Bower 2000a,b, Entwistle et al. 2006, 2010a,) it is suggested that holistic care is everyone's responsibility, especially in light of comments made by patients in this study that they want to be seen as persons, not merely as patients. However it is also recognised that the current model of consultation does not always lend itself to this approach (Gabe et al. 2004, Fischer and Ereaut 2012).

The skills witnessed and reported in relation to the nurses in this study link closely to the literature on advanced practice and expertise (Manley 1997, Manley and Garbett 2000, Manley et al. 2005) which describes attributes of holistic practice knowledge, knowing the patient, saliency and skilled know-how, all of which were witnessed in the nurses in this study. The nurses in this sample were all in post for at least 10 years and had worked together for that time which may explain why they appeared to command so much respect from patients and the other HCPs. This may also explain their extensive personal, ethical and aesthetic knowledge (Carper 1978) of patients and systems. It is clear that these nurses are working at advanced levels as evidenced by their autonomy, experience, clinical leadership, and specialist knowledge, (Benner 1984, Patterson and Haddad 1992, Manley 1997, ICN 2002, Daly and Carnwell 2003, Bryant-Lukosius et al. 2004). However the literature on advanced nursing discriminates between Specialist nurses (CNS') and Advanced nurses. Specialist nurses are said to possess knowledge which focuses on technical skills, derived from medical ideology (Sutton and Smith 1995), on select populations that are characterised by certain health problems (Paterson and Hadad 1992). This could apply to the nurses in the case. Contrastingly advanced nurse practitioners are expected to possess a higher level of theoretical knowledge (to Masters level) and be visionary, problem solvers, reflectors, enablers, leaders and risk takers who are willing to push boundaries and locate the client centrally (Paterson and Hadad 1992, Manley 1997). Whilst none of the nurses in this case are educated to Masters level, observation of their practice, reflections at interview (and to some extent my prior knowledge of them) evidenced some of these

attributes. Thus it would appear that the role is still subject to blurring and confusion (Carnwell and Daly 2003)

These nurses they may not be typical of other specialist nurses or teams. However other literature supports the value of nurse specialists (Brooten et al. 2002, 2012 Griffiths et al. 2013) and acknowledges that length of time in post and experience are important factors that influence the “dose effect” of advanced nurses (Brooten et al 2012). Similarly to Wilson’s (2007) study, nurse specialists in this study appeared not to feel threatened by patients. This may also be explained by their years of experience and senior grades and be specific to this case. Perhaps these experienced nurses are more empowered and self-confident such that they do not feel threatened by expert patients, unlike more novice nurses (Benner 1984, Wilson 2007).

Nurses used advanced skills to advocate, decision-make, and generally get what they wanted. As discussed earlier (p110) sometimes they played the doctor-nurse game and the doctors were aware of this, but played along. This practice perhaps contradicts the notion of advanced practice as it might be argued that continuation of the game preserves the *status quo* and fails to push the boundaries of nursing further. This is an area worthy of further exploration.

Of all the team members nurses are perceived to have the greatest holistic knowledge of patients and this is perceived as important by patients as it allows them to be seen as persons in their own right with competing agendas and lives outside CF.

For the nurses this knowledge allowed them to advocate within the team; for example when they felt patients were being asked to take on more treatments that were out with their capabilities due to competing demands.

Despite appearing to be the busiest people in the team there was a perception by patients that the nurses had the most time for them.

Nurses acknowledged that they were privileged in being able to see patients in their own environment which allowed them to view them more holistically than other

members of the team. Further, the nurses acknowledged that with experience they have learned to multi-task. For example whilst performing procedures such as central line flushing they could seemingly chat to patients but all the while were assessing them physically and emotionally, as well as seeking information on issues that were important to patients, such as benefits, equipment maintenance and supplies. This is also in keeping with the literature on advanced practice (Benner 1984, Manley et al. 2005).

Nurses are patients' first point of contact when they want to be seen, or they have an issue that requires intervention, thus the greatest frequency of contact with HCPs is usually with the nurses. Furlong and Smith (2005) assert that autonomy in clinical practice demands high levels of accountability, responsibility, and expert skill in the diagnosis and treatment of acute or chronic illness. It would appear that much of these skills are exhibited by the nurses in this sample and I witnessed several episodes where the junior doctors looked to them for advice and support. Despite an increase in the complexity of their nursing roles, (Srivastava et al. 2008) for example; insertion of central lines, spirometry testing, venipuncture, interpretation of results, what appears to be important to patients in this study are nurses personal and ethical knowledge of them and their holistic approaches to care. This is congruent with the work of Taylor et al. (2008) who found in their literature review of young people with chronic illness that the nurses were viewed as most important in the HC team with regard to support.

The articulation of nursing and its value have traditionally been difficult to measure due to the huge variance in the work that nurses do and the difficulty of quantifying concepts such as support or compassion (Cockerill et al. 1993, Friese and Beck 2004, O'Connor et al. 2009). More recently there have been attempts to measure nursing's worth especially in light of the development of advanced nursing roles (Manley and Garbett 2000, Brooten et al 2002, 2012, Griffiths et al. 2013). Support from nurses in advanced roles has resulted in benefits in several areas including functional improvement, improvement in mental health, morbidity, mortality, increased patient

satisfaction, reduced in-patient stays, improved symptom control, reduction in chemotherapy side effects and cost benefits (Breden et al. 1999, Brooten et al 2002, RCN 2010, Brooten et al.2012, Griffiths et al. 2013). This work adds to this body of knowledge.

As stated earlier, HCPs recognised the nurses as the most powerful members of the HC team. Whilst the power of nursing is well evidenced in relation to their relationship with patients (Thorne and Henderson 1999, Beiring 2002, Henderson 2003), it is suggested that historically nursing as a profession was perceived to be an oppressed group with minimal power, especially in relation to medicine (Davies 1995, 2004). Perhaps then the tide is turning. Whilst this finding cannot be generalised out with this small study, it is suggested there is scope for more research in this area.

### **7.5.2 Enablers: Mutual respect**

Mutual respect was afforded to both parties by the other as evidenced by the bureaucratic format which was observed at clinic, the ability to negotiate with each other, and respect for patients' experiential knowledge. Both parties talked about learning from each other which implied a level of partnership. Patients felt it was important that their experience was viewed as an important contributor to the discussions. HCPs reflected on how their styles of management had changed in relation to listening to patients' stories. For example, one HCP admitted to always being swayed by the numbers- the objective measurements of lung function in- their early days in the role. Now this HCP acknowledges that they err more towards the patient history before they even consider the numbers and draw on patients' experiential knowledge (Lawton 2003, Tyreman 2005a, Badcott 2005, Stoddart and Bugge 2012). Thus as indicated in the literature (McQueen 2000, Hook 2006, Cahill et al 1996,1998 ) respect as an attribute of partnership appears to be perceived as present in this sample. However this change in the HCP's practice was also influenced by their belief in the expertise of a particular patient and would not be a strategy that they adopted for all patients. This was also acknowledged by others in the team, who suggested that not all patients who

perceived themselves as experts were seen as such by the team. The concept of expertise is explored in the next section.

## **7.6 How do expert patients negotiate care? Defining expert patients and their practices**

Almost exclusively the young people in the sample were uncomfortable with the term “expert”. They acknowledged their wealth of experience and their ability to be in tune with themselves and know when something, however subtle, was not right. They preferred to use the term “experienced” as an adjective that would describe them. This experience although informed by some empirical knowledge was largely concerned with personal knowing of their bodies in response to their condition, which is individualised. For example, for some fatigue might be the first symptom of an exacerbation but for others it might be feeling bloated or constipated. Patients rejected the notion of expertise in relation to new symptoms. Thus, they were comfortable with recognising symptoms of all too familiar exacerbations, but were completely thrown out of their comfort zone when faced with something new such as haemoptysis or anaphylaxis. At this point all notions of expertise are discarded and patients recognised that they revert to becoming dependent on the HCPs for their empirical knowledge and experience. This finding resonates with previous studies (Paterson et al. 2002, McIntosh and Runciman 2008). The latter suggest that it is not always appropriate to negotiate but is situation and context-dependent. In their evaluation study situations where no negotiation took place were not viewed as against patients best interests but usually occurred where a quick decision needed to be made or parents were at breaking point. Pilnick and Dingwall (2011) also argue that there are times when the asymmetric relationship between physician and patient should be accepted and perhaps this time is when patients are faced with new unfamiliar symptoms.

Similarly Paterson et al. (2002) found that whilst as many as twenty one self-care decisions were witnessed during observation periods in patients with Type 1 diabetes, when faced with new issues patients sought specialist advice, (Paterson et al. 2002). Hill et al (2013) in a study that asked patients about autonomy preferences found that whilst patients expressed a desire for autonomy in general, when faced with scenarios they deferred to medical authority. Hill et al. (2013) suggest that this deference was associated with increased patient satisfaction. Further, they argue that choosing to defer to medical authority in a trusted relationship is in itself a form of patient autonomy. Thus the current study supports previous literature that suggests that expert patients draw on experiential knowledge and "body listening" (Paterson et al. 2002) to inform decision making but defer to specialists in the face of uncertainty or new symptoms.

Tyreman (2005b) suggests that expert patients lack phronesis: the ability to make decisions in uncertainty, which is associated with the domain of professionals.

Prior (2003) asserts that what patients report is change without knowledge of the disease processes that inform this change. This is affirmed by Tyreman (2005a) who suggests that expertise in patients is in relation to their experience of illness, as compared to physicians whose knowledge is in relation to disease. This finding links with the literature which differentiates between different types of knowledge in the professional and lay domains (Prior 2003, Tyreman 2005a, Badcott 2005), such as empirical, experiential, aesthetic and, intuitive knowledge, with empirical knowledge in expert patients being the most contested area (Wilson 2007). HCPs were most vocal in their reservations of patients expertise in this area, which is in keeping with previous work (Prior 2003, Chapman and Bilton 2004) that suggests surprisingly low empirical and technical knowledge in young people with CF.

Prior (2003) similarly found symptom talk in her study was of a superficial nature. Rather than debate which type of knowledge is most important, Tyreman (2005b) asserts that what is important is defining who takes responsibility for what (illness/disease), which involves defining boundaries, expectations and agreeing roles



and responsibilities within the patient-physician interaction to ensure collaboration. As previously discussed (p144) it is not clear that this happens currently within the study.

HCPs recognised that patients used the internet and social media to source and share information but asserted that this made them informed rather than expert. At other times they recognised that their knowledge was misinformed (Prior 2003) and suggested that there were patients who perceived themselves to be experts but who in their opinion were definitely not. Thus it would appear that the term expert patient does not sit well with patients, HCPs or the literature. Furthermore, the attributes of expertise; profession, authority, role position and title as described by Nuamanem-Tuomela (2001) appear to be those associated with the professional expert rather than the patient as expert.

## **7.7 The expert patient as navigator**

HCPs in this study were quick to suggest that patients in this sample were expert in relation to knowledge of systems and how to navigate them. They cited many examples of how patients “knew which buttons to push” in order to get what they wanted, or expedite care. Examples of this included circumventing clinic and asking nurses to make referrals for non-CF related issues that would usually be made by GPs (p120), or directly self-referring to the ward rather than attending clinic. Another strategy was the pretence of worsening health in order to start IV therapy in anticipation of holidays, despite the absence of an exacerbation. The rationale was to ensure they were in the best health before their holiday, a strategy that seems on the face of it to be one of common sense, as becoming ill when abroad may result in increased disruption and cost in terms of health and resources, at a later stage. However, to ask for this directly may have resulted in refusal and so alternative strategies were adopted. Thus knowledge of systems may be an important attribute of the expert patient.

There are several reasons offered as to why patients may appear to “play the system”. Patients have to plot a course through many systems and deal with large numbers of

personnel in their day-to-day management of chronic illness. This finding resonates with Wilson's (2007) study of the expert patient as "navigator". In addition patients in this study showed frustration of systems which require them to continually retell their stories and to be given advice that they have already rejected (p122). This is congruent with previous literature (Thorne et al. 2000, LTCAS 2008). Further, the sheer amount of time that patients must devote to managing treatments (Sawicki et al. 2008), attending appointments, organising drugs and equipment may result in them taking short-cuts (such as circumventing the clinic) in order to preserve the normalcy of life to include non-CF related priorities such as work, holidays, children and home life. Instead of challenging systems it is clear that some patients have developed other strategies such as pretending acceptance but in reality using covert rejection such as the use of covert administration of medicines (p243) and sifting selecting and discarding information for the sake of an easier life.

HCPs almost unanimously agreed that engagement and experiential knowledge were the most important attributes of the informed patient which assisted in partnership and negotiation of care. HCPs also acknowledged that informed patients were not necessarily those who were most compliant and that some had made conscious choices not to adhere to certain treatments such as nebulised therapies.

Wilson (2007) found that HCPs associated ideal patients with positive compliance. This was not specifically addressed in this study, although the converse may be said to have been a finding; that non-compliant patients; particularly young adolescents who were perceived to be non-compliant were also perceived by HCPs to be some of the most challenging (p117).

Other attributes of the expert patient that were suggested by HCPs included eloquence, empowerment and the ability to self-manage. Deconstruction of self-management revealed concepts such as monitoring the effect of treatments, titrating treatments according to health status; such as increasing physiotherapy or decreasing exercise, medicines management, forward planning with regard to: supplies, holidays, events and

anticipated health aberrations such as hypoglycaemia, or anaphylaxis. These decisions are informed by “body listening” (Paterson et al. 20002) and through the practice of “vigilance”, Koch et al. (2004). Further, as highlighted by one HCP; patients undertake these practices 99% of the time, without supervision. This is in keeping with Rogers’ (2009) assertion that patients have always self-managed, but that self-management has become redefined from a bottom up to a fashionable top down approach which has been adopted as policy (DoH 2005b).

Expertise in self-management was referenced frequently in patient interviews and witnessed during consultations: with patients’ questioning side effects of drugs, organising extra drugs for weekends away, querying doses of drug, requesting results and querying the implications of investigations. This questioning was sometimes direct and at other times patients used cues and concerns, a finding consistent with the literature and discussed fully on page 140.

These practices evidenced high levels of engagement with HCPs. Prior (2003) suggests that the development of such skills was a necessity for some patients in order to overcome medical hegemony, however it is suggested here that these practices are more likely to be an embedded part of living with a long term condition since birth or early childhood, coupled with a new generation of consumers of healthcare. This is confirmed by a study by Williams et al. (2009) which suggests that treatments become embedded and routinised as a normal part of life. Contrary to Bury’s (1982) theory of biographical disruption, this group has never experienced anything other than a life with chronic illness thus it has become a normalised part of their biography. Whilst the literature suggests that not all patients want to engage in partnership (Waterworth and Luker 1990, Stoddart and Bugge 2012), there was evidence of at least partial engagement from all patients in this study.

In this study virtually the entire patient sample saw CF as not having much of an impact on their lives, but when probed their treatment demands were burdensome. This

finding supports the body of literature cited in the literature review (p25) which recognises the concepts of normalcy and embeddedness as integral to living with a long-term condition (Bury 1982, Thorne and Robinson 1989, Kralik et al. 2001, Lowton and Gabe 2003, Charmaz 2006, Badlan 2006, Williams et al. 2009). Patients revised old norms and replaced them with strategies that continued to preserve the concept of normalcy. For example when questioned about how far they could walk the respondent replied that they didn't walk anywhere they took the lift, (p124) thus, loss of mobility was not a limitation but was normalised through the use of a car to get from A to B.

It is suggested that minimising the impact of disease is one way of coping (Abbot et al. 1995, Goldbeck and Babka 2001, Sawicki et al 2008, Taylor et al. 2008, Casier et al. 2011) and links to the concept of normalcy discussed earlier (Thorne and Robinson 1989, Bury 1992, Charmaz 2006, Williams et al. 2009). If being seen as normal is perceived as more important to young people with CF than optimising health, then tensions will inevitably result between patients and HCPs. Perhaps it is unrealistic to expect both parties to share the same agendas given that the nature of healthcare is usually concerned with optimising health. However respecting autonomy may be seen as equally important in this consumerist age and it is in accommodating these two sometimes conflicting perspectives that discord may occur. Thus negotiating a way forward is essential and in this study negotiation was witnessed frequently.

## **7.8 Summary: Putting it all together**

This chapter has analysed the findings of the research through a narrative discussion. Having constructed this narrative, it was felt that diagrammatic representation would enhance a summary of the findings of the original research questions. Thus three methods are employed in the following chapter to illustrate this. Firstly a return to Hook's table of attributes of partnership, (table 15, p165). Secondly a conceptual framework (p168 ) is offered as a means through which to explain the partnership.

Finally a mind map which represents all of the findings (including those which were not discussed in the narrative) is presented in appendix 14 (p250).

## CHAPTER EIGHT: CONCLUSION

### 8.0 Introduction

This chapter highlights the new knowledge gained through the research process in the form of a conceptual model and revisits the research questions through Hook's model of partnership. A final visual representation of the research findings can be viewed in the mind map (Appendix 14, p250). Researcher reflections are also presented here in terms of the learning achieved through the doctoral process, the dissemination of the research findings and the implications for practice.

### 8.1 Comparison of findings to Hook's partnership model

Hook's table has been adapted to accommodate a third column which highlights the presence or absence of the said attributes as evidenced through the study's findings.

**Table 15: Revised partnership model (Adapted from Hook 2006)**

<b>Attributes</b>	<b>Associated terms</b>	<b>Was this witnessed in the study?</b>
Shared decision making	Negotiation, mutual goals, shared decision making	Yes in the main, yes HCPs will give quite a lot (too soft), but patients not always trusted to carry them out
Relationship	Mutuality, reciprocity, alliance	Respectful (frontstage) Committed, Levels of

		attachment?- linked to duration? Emotional labour
Professional competence	Expertness, empowering, supports change	Patients prefer “experienced” professionals recognise this but some sceptical about expertise Accountability vs trusting the patient in the consultation model
Shared knowledge	Mutual learning, common understanding	Both parties acknowledge learning from the other. HCPs acknowledge huge burden of care but ask for more
Autonomy	Self-determined, expert in own care, ownership	Recognition by HCPs of experiential knowledge, but sometimes patients perceive they’re not heard
Communication	Two-way, honest, open, confidential	Encouraged. Patients openly non-compliant
Participation	Engaged, monitors,	Lots of evidence in

	takes charge	patients of self-monitoring. Even those who professed to be unengaged were self-monitoring
Shared power	Equal, engages in trade-offs, shared control	Not always, shifts according to context, meeting in middle witnessed. Patients can be perceived as intimidating

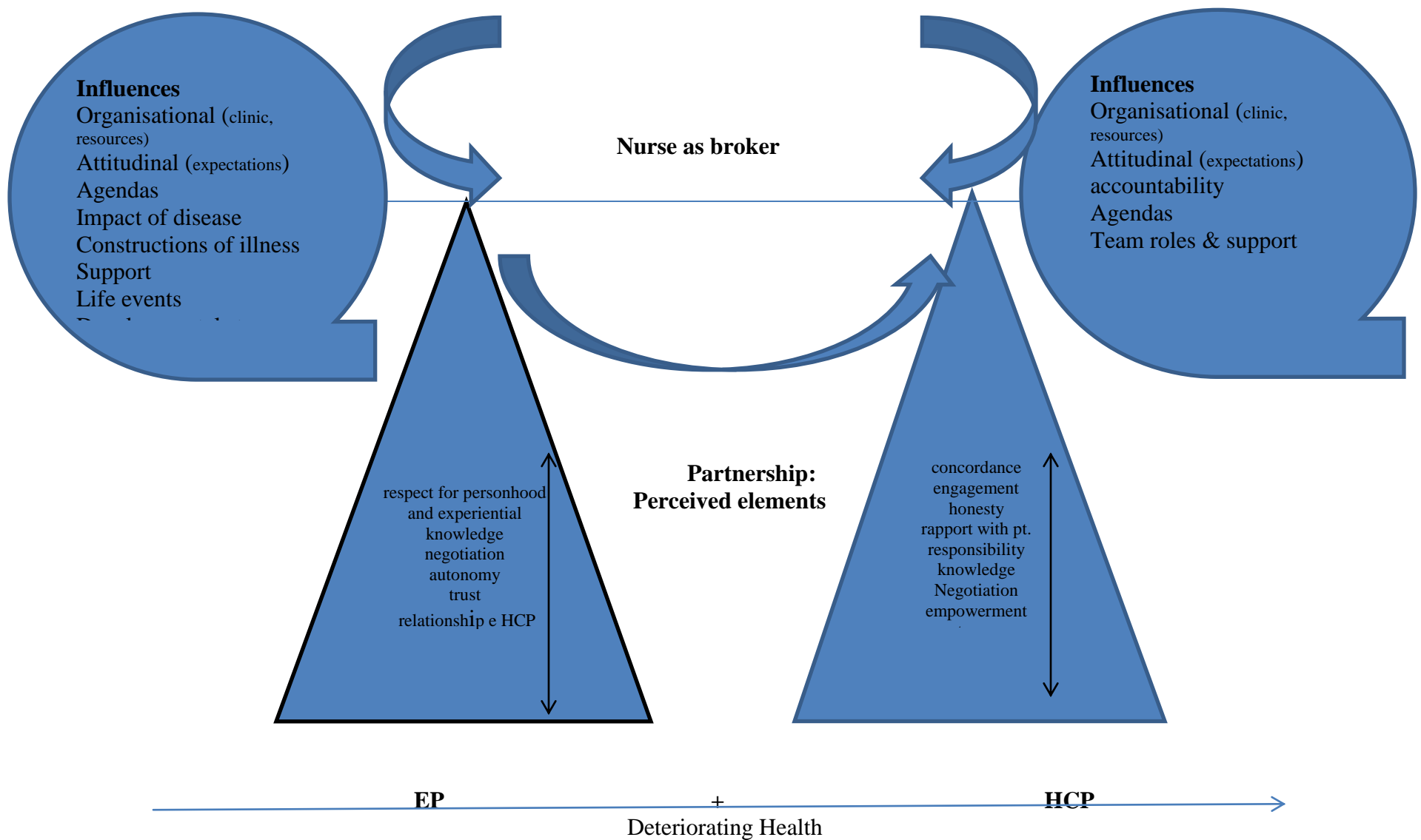
## 8.2 Conceptual Model of Partnership (fig 1)

The proposed conceptual model (p168) views the partnership as a set of scales, with on one side the *experienced* patient (EP) and on the other the HCP. Within each triangle in the model are the perceived desired elements of the other partner; thus HCPs desire concordance, whilst patients desire respect for personhood. The arrows indicate that these desired elements may move in order of preference, according to the situation, thus the model can be viewed as dynamic. The line along the bottom indicates that the partnership occurs in the context of deteriorating health. On either side of the scales are the factors (enablers or inhibitors) that may tip the partnership out of balance. Finally the nurse is seen as being the connected influence which preserves the balance between the partners and the factors.

The mind map, (appendix 14, p250), shows all the concepts identified in the study including those which did not merit a fuller discussion in the narrative.



**Fig 1: A proposed conceptual model of partnership**



### 8.3 New knowledge

New knowledge generated through the research is highlighted in table 16. Implications of this new knowledge are then discussed.

**Table 16: New knowledge emerging through the research thesis**

Theme	New knowledge
Experiences of partnership	HCPs as too soft
	patients as powerful
	Attachment and commitment in long term partnerships
	How nurses use power
Attributes of the expert patient	The expert patient as navigator (new context)
Constructions of illness	Impact of developmental stage and life events on adherence

Several issues are worthy of note. Firstly, the term expert patient remains contested, not least by the patients themselves in this study who preferred the term “experienced”. Expertise was perceived as only being present when dealing with the familiar and recognisable parameters. When new symptoms/ drugs/ situations arose patients deflected expertise back to HCPs. Thus perhaps it is time to revisit the term and employ one with which patients and HCPs are more comfortable.

Secondly, there was evidence of partnership between most of the young people in this study and the HCPs with whom they interacted. HCPs were prepared to negotiate,

young people were usually not afraid to challenge, and consultations were tailored to individuals where possible. HCPs acknowledged that building relationships and encouraging open and honest communication was challenging with new transitioning patients. Respect for autonomy was evident on both sides of the partnership and HCPs acknowledged patients experience as valuable in negotiating care. Where there were difficulties this was often linked to issues of trust in patients' accounts of adherence to treatments or medicines, or less frequently to patients' perceptions of not being listened to in the consultation. This may impact on development of relationships where trust could be discussed openly or challenged. This may be an area for development which could be further explored within the patient HCP relationship.

Thirdly, the structures and setting where most of the interactions between HCPs and patients take place preserved the ceremonial order of the clinic first seen in the 1970s. It is suggested that this ritualistic, physician-driven model is no longer fit for purpose in a mutual twenty first century NHS. Although it is recognised that mutuality is not the desire for all, consultations should be tailored to patients' needs. Whilst most consultations were observed to be context-specific in this study, they were viewed within the confines of the ceremonial order of the clinic and this limited a true partnership approach.

Finally the power of the nurses was noted and their pivotal role as the linchpin of the partnership relationship. Although there were only three nurses in this sample, their impact appears to be far reaching as described by both patients and HCPs. This is worth disseminating widely, given nursing's history of lack of power and adds to the body of evidence regarding the value of advanced nursing roles.

## **8.4 Implications for practice**

Several recommendations are offered for consideration and potential areas for future research are suggested.

Firstly, it is suggested that at the time of transition from paediatric to adult care, ground rules are negotiated, agreed and revisited regularly. This should include roles,

responsibilities and expectations of and from both parties in the partnership. This may help to foster a relationship based on honesty and trust, where both parties feel comfortable challenging the bureaucratic format currently seen. This in turn may foster a culture of openness regarding patients' candidness and HCPs trust of accounts of adherence or non-adherence. Team ground rules might also be formulated so that there is a consistency of approach which discourages patients from playing staff off against each other, and discourages formation of "in-groups" and "out-groups" of staff.

Further development in the use of motivational interviewing and use of decision-making tools, (Coulter and Collins 2011), are already being discussed within the current case and evidence from the literature suggests they have shown to increase knowledge, reduce passivity and reduce decisions for invasive treatments and procedures which can in turn reduce costs (O'Connor et al. 2009). However Coulter and Collins (2011) acknowledge that it takes time and training resources to facilitate this practice. None the less adoption may encourage further good practice in negotiation of care. This may also enable HCPs to discover what patients' agendas and priorities are in relation to their biomedical and social worlds.

Shifting to a needs-centred approach to consultation will require HCPs to place trust in patients to prioritise their own concerns and may have implications for issues such as accountability and information gathering to inform the CF database. Telehealth may be one method which enables a more patient-centred approach. For example patients could complete and send in questionnaires electronically before the consultation which addresses many of the details they would be asked at clinic. An example of this is taking a dietary history. Currently some patients already come prepared with their three day dietary histories and this could be extended to other areas. This would decrease the amount of repetitive questions that patients are subjected to at the clinic. In addition to this, questionnaires could indicate what the key issues are that patients want to discuss. This is already happening in other clinics outside the UK (Hubert et al. 2013) and has revealed that biomedical issues are not always patients main priorities, a

finding consistent with the literature (Bury 1991, 2005, Charmaz 2002, Taylor and Bury 2007. Finally Fischer and Ereaut (2012) suggest that not all patients require the same time slot at clinic and evidence suggests that clarifying this at the outset of the consultation and organising around it works well. Thus pilot studies in all of these areas could be instigated in a co-operative collaborative process.

Telehealth options could also be extended to virtual clinics through the use of skype videophone or telepod (Simon et al. 2000, Scottish Centre for Telehealth and Telecare (SCTT) 2013) which allow "face to face" consultation via an interface and transfer of data such as spirometry. This would negate the risk of cross infection at clinic, reduce dead time for patients and may reduce non-attendance rates. This model has been piloted in other groups with long term conditions with encouraging outcomes including higher patient satisfaction, reduced exacerbations and in-patient admissions (SCTT 2013). However this model is resource-intensive and similar to Gortzis (2009) recommends significant investment in training and support for staff and patients. Thus perhaps this needs to be considered as part of a suite of existing and novel measures. A systematic review (Eland-de Kok et al. 2011) of twelve RCT's investigating benefits of Telehealth compared to or in addition to usual care in groups with a long-term condition found small to moderate improvement in health outcomes, where Telehealth was added to or compared to usual care. However cost benefits were not proven and further research in this area is recommended.

Adoption of a consultation model driven by patient issues could operate alongside this system, as the tick box information required for the database could be gathered electronically before the "face-to-face" (virtual or actual) event. Patients and HCPs would also be encouraged to give feedback electronically on the new consultation process so that changes could be made as an on-going process.

Patient-held records may assist in this patient centred approach and encourage patient responsibility and ownership.

As discussed previously, whilst the nurses are highly valued by all parties there is scope for further development of their role through up-skilling to include prescribing, advanced assessment and nurse-led clinics. This may mitigate the problems they describe around accessing junior doctors for these skills but also needs to take into consideration existing workload.

## **8.5 Dissemination**

Preliminary findings from the study have already been presented at an international conference (MacDonald 2013a,b). It is expected that this work will be published in peer reviewed journals and at further national and international conferences. I plan to produce a leaflet for the patients and carers involved in the study, summarising the findings. Finally a return to the study site is planned to discuss the final results with the HCPs who took part in the study and discuss ways to take the research forward.

## **8.6 Future Research**

As stated earlier this was a small cross sectional study in one setting. Further research might explore the nature of partnership across more than one setting longitudinally. Additionally future research may be warranted in the exploration of attachments in the HCP/patient relationship, given the long duration of these relationships.

Discussions have already taken place with those involved in the original research to consider ways forward and have been encouraging. It is hoped in light of the findings to pilot new ways of operationalising the clinic, using a Participatory Action Research Approach which involves service users from the outset. This might include setting of ground rules, devising pre-clinic questionnaires and considering the use of Telehealth. Additionally, pilot of decision aids is a potential way forward to increasing patient involvement. These processes need to involve patients in the planning, implementation and evaluation of each phase in the spirit of true partnership. Findings are to be presented in a patient newsletter and requests for patient volunteers to engage in the

process will be pursued. It is anticipated that research funding will be sought to develop this further if there is consensus of agreement.

The concept of the expert patient is still contentious and there is scope for further exploration into the terminology, attributes and outcomes associated with the concept. Further research might extend to continuation of the doctor-nurse game and the effect of advanced practice on game playing. Finally research might consider the concept of the expert family, as it suggested that even within a small study such as this family support and experience are essential and embedded within the social context of long-term conditions.

## **8.7 Reflection on Personal Learning**

This doctoral journey has been a revelatory one. Little did I realise when I signed up for general nurse training in the 1980s that I would be studying for a doctorate thirty years later. My maturity in years can be matched by the maturity that I have seen develop in my writing through the doctoral process and has been evidenced through feedback and discussion with my director of studies and the developmental nature of the writing through this thesis. Further, my continued passion for research has been fuelled in the writing of this thesis and has taught me the importance and value of good supervision. Sometimes the learning has been as a result of failure to be meticulous in my organisational skills and at other times as a direct result of being pushed out of my comfort zone (e.g. challenging or being challenged by supervisors or the ethics panel). All of these learned skills will make me a better researcher and I hope a better teacher. I have also come to realise at doctoral level that there are rarely right or wrong answers, only more questions.

## 8.8 Conclusion

This study has explored how young “expert patients” living with cystic fibrosis (CF) and the healthcare professionals (HCPs) with whom they interacted perceived partnership and negotiated care.

Through the literature review concepts of living with chronic illness and normalcy, the expert patient and partnership in relation to social interactions between patients and HCPs have been explored. The conceptual framework underpinned by Social Constructionism and Symbolic Interactionism, informed by a Descriptive Interpretivist methodology was justified. A discussion of the methods employed; non-participant observation and semi-structured interviews followed.

Data were analysed thematically using the five stages of “Framework” (Ritchie and Lewis 2003) a matrix based approach to qualitative analysis. Three major themes emerged from these data: Experiences of partnership, attributes of the expert patient and constructions of illness. Multiple subthemes were also presented, including the power of the nurses, normalcy and the ceremonial order of the clinic. Issues of rigour and ethics were addressed and explanations for the findings offered. Limitations of the study were also addressed.

Implications for practice suggest the need for ground rules outlining both parties’ roles and responsibilities in partnership, a remodelling of the clinic format to ensure patient centredness, including the use of decision aids, up-skilling of CNS’ and a consideration of the role of Telehealth in any new proposed model. Dissemination and areas for further research were highlighted.

Lansley (2010) states there should be

“no decision about me without me”



and recognises that different groups of patients might have different expectations about levels of shared decision making or patient engagement. They suggest that we may be stuck in relationships with HCPs that no longer meet current needs. The current study whilst showing some excellent examples of shared decision-making and negotiation, is rooted in a bureaucratic format that suggests it is no longer fit for purpose. This work goes some way to evidence the need for change.

Patients with cystic fibrosis born in the year 2000 can be expected to have a median life expectancy of 50 years. It is anticipated that during almost all of this time they will live with and self-manage their condition and it is crucial that the healthcare system is flexible enough to fully support individual autonomy and choice.

## List of References

ABBOTT, J., DODD, M. and WEBB, A.K., 1995. Different perceptions of disease severity and self-care between patients with cystic fibrosis, their close companions, and physician. *Thorax*, vol. 50, pp.794–6.

ABBOTT, J., DODDS, M. and WEBB, K., 1996. Health perceptions and treatment adherence in adults with cystic fibrosis. *Thorax*, vol. 51, no. 12, pp. 1233-1238.

ABBOTT, J., DODDS, M., GEE, L. and WEBB, K., 2001. Ways of coping with cystic fibrosis: Implications for treatment adherence. *Disability and Rehabilitation*, vol. 23, no.8. pp. 315-324.

ABBOTT, J., 2013. *An Overview of Coping and Resilience in people with Cystic Fibrosis*. [Seminar]. European Cystic Fibrosis Convention. Lisbon: Portugal.

AGAOGI, A., 2013. *Academic writing: why no "me" in PhD?* The Guardian Higher Education Network. [viewed 30<sup>th</sup> October 2013]. Available from: <http://www.theguardian.com/higher-education-network/blog/2013/apr/19/academic-writing-first-person-singular>

ALEXANDER, J., HEARLD, L., MITTLER, J. and HARVEY, J., 2011. Patient–Physician Role Relationships and Patient Activation among Individuals with Chronic Illness. *Health Services Research*, vol. 47, no. 3/1, pp. 1201-1223.

ALDERSON, P., SUTCLIFFE, K. and CURTIS, K., 2006. Children as partners with adults in their medical care. *Archives of Disease in Childhood*, vol.91, pp. 300-304.

ANDERSON, J., 1981. The social construction of illness experience: families with a chronically-ill child. *Journal of Advanced Nursing*, vol. 6, no. 6, pp. 427.

ARMSTRONG, D., GOSLING, A., WEINMAN, J. and MARTEAU, T., 1997. The Place of Inter-Rater Reliability in Qualitative Research: An Empirical Study. *Sociology*, vol. 31, no. 3, pp. 597-606.

ARTHUR, S. and NAZROO, J., 2003. Designing Fieldwork Strategies and Materials. In: J. RITCHIE and J. LEWIS eds., *Qualitative Research Practice*. London: Sage, pp. 109-137.

BADCOTT, D., 2005 The expert patient: valid recognition or false hope? *Medicine, Health Care Philosophy*, vol 8, pp. 173-178.

BADLAN, K., 2006. Young people living with cystic fibrosis: an insight into their subjective experience. *Health and Social Care in the Community*, vol.14, no.3, pp. 264-270.

BALAGUER A, and ONZALEZ de DIOS J, 2012. Home versus hospital intravenous antibiotic therapy for cystic fibrosis. *Cochrane Database of Systematic Reviews*, Issue 3 Art no: CD001917.DOI

BALLAMINGIE, P., and JOHNSON, S., 2011. The Vulnerable Researcher: Some unanticipated challenges of doctoral fieldwork. *The Qualitative Report*, vol. 16, no. 3, pp. 711-729.

BARRETT, C., BORTHWICK, A., BUGEJA, S., PARKER, A., VIS, R. and HURWORTH, R., 2005. Emotional labour: listening to the patient's story. *Practice Development In Health Care*, Vol.4, no. 4, pp. 213-223.

BARRY, C.A., BRADLEY, C.P., BRITTEN, N, STEVENSON, F.A., and BARBER, N., 2000. Patients' unvoiced agendas in general practice consultations: qualitative study. *British Medical Journal*, vol. 320, pp. 1246-1250.

BAZELY, P., 2007. *Qualitative Data Analysis with NVivo*. London: Sage.

BEAUCHAMP, T. and CHILDRESS, J., 2009. *Principles of Biomedical Ethics*. 6th ed. New York: Oxford University Press.

BEE, H. and BOYD, D., 2010. *The Developing Child*. 12<sup>th</sup> ed. Harlow, New Jersey: Pearson.

BEIRING, P., 2002. Caring for the involuntary hospitalized adolescent: The Issue of Power in the Nurse-Patient Relationship. *Journal of Child & Adolescent Psychiatric Nursing*. vol.15 no.2, pp. 65-74.

BENNER, P., 1984. *From novice to expert: Excellence and power in clinical nursing practice*. Menlo Park, CA: Addison-Wesley.

BENSING, J.M. and VERHAAK, P.F.M., 2004. Communication in Medical Encounters. In: A. KAPTEIN and J. WEINMAN eds., *Health Psychology*. Oxford: Blackwell.

BENZIES, K.M. and ALLEN, M.N., 2001. Symbolic Interactionism as a theoretical perspective for multiple method research. *Journal of Advanced Nursing*, vol. 33, no. 4, pp. 541-547.

BERGER, K., 2005. *The Developing Person*. 6<sup>th</sup> ed. New York: Worth Publishers.

BERGER, P.L. and LUCKMAN, T., 1971. *The Social Construction of Reality: a treatise in the sociology of knowledge*. London: Penguin.

BERGIN, M., 2011. NVivo 8 and consistency in data analysis: reflecting on the use of a qualitative data analysis program. *Nurse Researcher*, vol. 18, no.3, pp. 6-12.

BETTANY-SALTIKOV, J., 2012. *How to do a Systematic Literature Review in Nursing*. Berkshire: Open University Press.

BIDMEAD, C. and COWLEY, S., 2005. A Concept Analysis of Partnership with clients *Community Practitioner*, Vol 78, no. 6, pp.203-208.

BILTON, D., 2013. *The Young Adult*. [Seminar]. European Cystic Fibrosis Convention. Lisbon: Portugal.

BLAKEMORE, S.J. and CHOUDHURY, S., 2006. Development of the adolescent brain: implications for executive function and social cognition. *Journal of Child Psychology and Psychiatry*, vol. 47, no. 3/4, pp. 296-312.

BLUEBOND-LANGER, M., 1996. *In the shadow of illness*. Princeton: Princeton University Press.

BLUMER, H. 1969. *Symbolic Interactionism: Perspective and method*. Englewood: Prentice Hall.

BOLTON, S.C., 2000. Who cares? Offering emotion work as a 'gift' in the nursing labour process. *Journal of Advanced Nursing*, vol. 32, no. 3, pp. 580-586.

BONDI, L., 2005. *Making connections and thinking through emotions: between geography and psychotherapy*. Institute of Geography, School of Geosciences, University of Edinburgh ed., Edinburgh.

BRADY, M., 2009. Hospitalized children's views of the good nurse. *Nursing Ethics*, vol. 16, no. 5, pp. 543-560.

BREDIN, M., CORNER, J., KRISHNASAMY, M., PLANT, H., BAILEY, C. and A'HERN, R., 1999 Multicentre randomised controlled trial of nursing intervention for breathlessness in patients with lung cancer. *British Medical Journal*, vol. 318 no. 7188, pp.901-4.

*Bristol Royal Infirmary Enquiry* 2001. London: HMSO. [Viewed 23<sup>rd</sup> Sept 2013]. Available from: [http://webarchive.nationalarchives.gov.uk/20090811143745/http://www.bristol-inquiry.org.uk/final\\_report/index.htm](http://webarchive.nationalarchives.gov.uk/20090811143745/http://www.bristol-inquiry.org.uk/final_report/index.htm).

BRITTEN, N., 1995. Qualitative interviews in medical research. *British Medical Journal*, vol. 311, no. 6999, pp. 251-253.

BROOTEN, D., NAYLOR, M.D., YORK, R., BROWN, L.P., MUNRO, B.H., HOLLINGSWORTH, A.O., COHEN, S.M., FINKLER, S., DEATRICK, J. and YOUNGBLUT, J.M., 2002. Lessons learned from 22 years of testing the Quality Cost Model of Advanced Practice Nursing (APN) Transitional Care. *Journal of Nursing Scholarship*, vol. 34, no 4, pp.369-375.

BROOTEN, D. YOUNGBLOT, J.M. DEOSIRES, W. SINGHALA, K., and GUIDO-SANZ, F., 2012 Global considerations of measuring effectiveness of advanced practice nurses. *International Journal of Nursing Studies*, vol.49, pp. 906-912.

BROWN, D., MCWILLIAM, C, and WARD-GRIFFITHS, C., Client-centred empowering partnering in nursing. *Journal of Advanced Nursing*, vol.53, no.2, pp. 160-168. BRUNER, J., 1991. The narrative construction of reality. *Critical Inquiry*, vol. 18, pp. 1-21.

BRYANT-LUKOSIUS, D., DICENSO, A., BROWNE, G. and PINELLI, J., 2004 Advanced practice nursing roles: development, implementation and evaluation. *Journal of Advanced Nursing*, vol. 48, no.5, pp.519-529.

BURR, V., 1995. *An Introduction to Social Constructionism*. London: Routledge.

BURY, M.K., 1982. Chronic illness as biographical disruption. *Sociology of Health and Illness*, vol. 4, no.2, pp. 167-182.

BURY, M., 1988. Meanings at risk; the experience of arthritis. In: ANDERSON, R., BURY, M. eds. *Living with Chronic Illness: the experiences of patients and their families*. London: Unwin Hyman.

BURY, M., 1991. The sociology of chronic illness: a review of research and prospects *Sociology of Health & Illness*, vol.13, no.4, pp. 451-468.

BURY, M., 2005. *Health and Illness*. Cambridge: Polity.

CAHILL, J., 1996. Patient participation: a concept analysis. *Journal of Advanced Nursing*, vol. 24, no.3, pp. 561-571.

CAHILL, J., 1998. Patient participation: a review of the literature. *Journal of Clinical Nursing*, vol.7, no.2, pp.119-128.

CALNAN, M. and GABE, J., 2001. From consumerism to partnership? Britain's NHS at the turn of the century. *International Journal of Health Services*, vol. 31, pp. 119-131.

CALNAN, M. and ROWE, R., 2008. Trust, Accountability and Choice (Editorial). *Health, Risk & Society*, vol. 10, no. 3, pp. 201-206.

CARPER, B., 1978. Fundamental ways of knowing. *Advances in Nursing Science*, Vol.1, no.1. pp. 19-34.

CARR, L.T., 1994. The strengths and weaknesses of quantitative and qualitative research: what method for nursing? *Journal of Advanced Nursing*, vol. 20, no.4, pp. 716-721.

CASIER, A., GOUBERT, L., THEUNIS, M., HUSE, D., DE BAETS, F., MATTHYS, D. and CROMBEZ, G., 2011. Acceptance and Well-Being in Adolescents and Young Adults with Cystic Fibrosis: A Prospective Study. *Journal of Paediatric Psychology*, vol. Jan 5, pp. 1-12.

CHAPMAN, E. and BILTON, D., 2004. Patient's knowledge of cystic fibrosis: genetic determinism and implications for treatment. *Journal of Genetic Counselling*, vol. 13, no. 5, pp. 369-385.

CHARLES, C., GAFNI, A. and WHELAN, T., 1997. Shared Decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Social Science and Medicine*, vol. 44, pp. 681-692.

CHARLES, C., GAFNI, A. WHELAN, T., 1999. Decision-making in the Physician- Patient encounter: revisiting the shared treatment decision-making model. *Social Science and Medicine*, vol. 49, pp. 651-661.

CHARLES, C., GAFNI, A. WHELAN, T., 2000. How to improve communication between doctors and patients. *British Medical Journal*, vol. 319, pp. 780-782.

CHARMAZ, K., 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, vol. 5, no. 2, pp. 168-195.

CHARMAZ, K., 1987. Struggling for self: identity levels of the chronically ill. *Research in the Sociology of Health Care*, vol. 6, pp. 283-321.

CHARMAZ, C., 1990. "Discovering" Chronic Illness; using Grounded Theory. *Social Science and Medicine*, vol. 30, pp. 1161-1172.

CHARMAZ, K., 2002. Stories and silences: disclosures and self in chronic illness. *Qualitative Inquiry*, vol. 8, pp.302-328.

CHARMAZ, K., 2006. Measuring pursuits, marking self: Meaning construction in chronic illness. *International Journal of Qualitative Studies on Health and Well-being*, vol. 1: pp.27-37.

CHARON, J.M. 2009. *Symbolic interactionism: an introduction. an interpretation, an integration*. New Jersey: Prentice Hall.

*CHILDREN'S Act* 2004. London: HMSO. [Viewed 29th Aug 2013]. Available from: [http://www.legislation.gov.uk/ukpga/2004/31/pdfs/ukpga\\_20040031\\_en.pdf](http://www.legislation.gov.uk/ukpga/2004/31/pdfs/ukpga_20040031_en.pdf)

CLARKE, A., 2006. Qualitative interviewing: Encountering ethical issues and challenges *Nurse Researcher*, vol. 13, no.4. pp. 19-28.

COCKERILL, R. O'BRIAN PALLAS, L. BOLLEY, H. PINK, G., 1993. Measuring nursing workload for case costing *Nursing Economics*, vol. 11, no.6. pp. 342-349.

COHEN, L., MANION, L. and MORRISON, K., 2007. *Research Methods in Education*. 6th ed. New York: Routledge.

COLLINS, S., DREW, P., WATT, I. and ENTWISTLE, V., 2005. Unilateral and Bilateral practitioner approaches in decision making about treatment. *Social Science & Medicine*, vol. 61, pp. 2611-2627.

CONNELLY, L.M., 2008. Research Roundtable: Pilot Studies. *Medsurg Nursing*, vol. 17, no. 6, pp. 411-412.

COONEY, A., 2011. Rigour and grounded theory. *Nurse Researcher*, vol. 18, no. 4, pp. 17-22.

CORBIN, J.M. and STRAUSS, A., 1985. Managing Chronic Illness at home: three lines of work. *Qualitative Sociology*, vol. 8, pp. 224-247.

CORBIN, J.M. and STRAUSS, A., 1988. *Unending Work and Care: Managing Chronic Illness at Home*. San Francisco: Josey Bass.

CORBIN, J. 2003. The body in health and Illness. *Qualitative Health Research*, vol.13, no.3, pp.256-267.

CORLETT, J. and TWYLCROSS, A., 2006(a). Negotiation of parental roles within family-centred care; a review of the literature *Journal of Clinical Nursing*, vol. 15, no.10, pp. 1308-1316.

CORLETT, J. and TWYLCROSS, A., 2006(b). Negotiation of care by children's nurses: lessons from research. *Paediatric Nursing*, vol.18, no.8, pp.34-37.

COSTER, S. and NORMAN, I., 2009. Cochrane review of educational and self-management interventions to guide nursing practice; A review. *International Journal of Nursing Studies*, vol. 46, pp. 508-528.

- COULTER, A., 1999. Paternalism or partnership? *British Medical Journal*, vol. 319, pp. 719-720.
- COULTER, A., 2002. *The autonomous patient; ending paternalism in medical care*. London: TSO.
- COULTER, A. and COLLINS, A., 2011 *Making shared decision-making a reality*. London: Kings Fund.
- COULTER, A., 2012a. *Leadership for patient engagement*. London: Kings Fund.
- COULTER, A., 2012b. Patient engagement--what works? *Journal of Ambulatory care Management*. vol. 35, no.2, pp.719-720.
- COULTER, A., SAFRAN, D. and WASSON, J., H., 2012. On the language and content of patient engagement. *Journal of Ambulatory Care Management*, vol.35, no.2. pp.78-9.
- COYNE, I., 2006. Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, vol. 15, pp. 61-71.
- COYNE, I., 2007(a). Disruption of parent participation: nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing*, vol.17, no.23, pp. 3150-3158.
- COYNE, I., 2007 (b). Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies*, vol. 44, pp.893-904.
- COYNE, I., 2008. Children's participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies*, vol.45 no.11, pp.1682-1689.
- COYNE, I., 2010. Accessing children as research participants: examining the role of gatekeepers. *Child: Care, Health and Development*, vol. 36, no. 4, pp. 452-454.
- CREER, T.L. and HOLROYD, K.A., 2006. Self-management of chronic conditions: the legacy of Sir William Osler. *Chronic Illness*, vol. 2, pp. 7-14.
- CROTTY, M., 1998. *The foundations of Social Research*. London: Sage.
- CUTLIFFE, J. R. and WARD, M., 2004. *Critiquing Nursing Research*. Wiltshire: Quay.
- CYSTIC FIBROSIS TRUST, 2011. Standards for the Clinical Care of Children and Adults with Cystic Fibrosis in the UK. Kent: CF Trust.
- CYSTIC FIBROSIS TRUST, 2013. [Viewed 28th August 2013]. Available from: <https://cysticfibrosis.org.uk/about-cf.aspx>



DAISKI, I., 2004. Changing nurses dis-empowering relationship patterns. *Journal of Advanced Nursing*, vol. 48, no. 1, pp. 43-50.

DALY, W. and CARNWELL, R., 2003. Nursing roles and levels of practice: a framework for differentiating between elementary, specialist and advancing nursing practice. *Journal of Clinical Nursing*, vol. 12, no.2, pp.158-67.

DARZI, A., 2008. *High Quality for All*. London: Department of Health,.

*Data Protection Act*. 1998. London: HMSO.

DAVIES, C., 1995. *Gender and the professional Predicament in Nursing*. Bucks: Open University Press.

DAVIES, C., 2004. Political leadership and the politics of nursing. *Journal of Nursing Management*, vol. 12, pp. 235–241

DAVIES, N.J., 2010. Improving self-management for patients with long-term conditions. *Nursing Standard*, vol. 24, no. 25, pp. 49-56.

DAWOOD, M., 2005. Patient centred care: Lessons from the medical profession *Emergency Nurse*, vol.13, no.1, pp. 22-27.

DENZIN, N., LINCOLN, Y., 2000. *Handbook of qualitative research*. 2<sup>nd</sup> ed. London: Sage.

DEPARTMENT OF HEALTH,(DoH) 2000 *The NHS Plan*. London.: HMSO.

DEPARTMENT OF HEALTH, (DoH) 2001 *The Expert Patient- a new approach to chronic disease management for the 21st century*. London. Stationery Office.

DEPARTMENT OF HEALTH, (DoH), 2004. *Choosing Health*. London: Department of Health.

DEPARTMENT OF HEALTH, (DoH) 2005(a). *National Service Framework for Long Term Conditions*. London: DoH.

DEPARTMENT OF HEALTH, (DoH) 2005(b). *Self Care-A Real Choice*. London: DoH.

DEPARTMENT OF HEALTH, (DoH) 2006 *Our Health Our care: a new direction for community services*. London: Department of Health.

DEPARTMENT OF HEALTH, (DH) 2010. *Equity and Excellence: Liberating the NHS*. London: HMSO.

DEPARTMENT OF HEALTH, (DH) 2013. *Improving quality of life for people with long term conditions*. London: HMSO. [viewed 23<sup>rd</sup> Sept 2013]. Available from: <https://www.gov.uk/government/policies/improving-quality-of-life-for-people-with-long-term-conditions>.

DICKSON-SWIFT, V., JAMES, E.L., KIPPEN, S. and LIAMPUTTONG, P., 2006. Blurring boundaries in Qualitative Health Research on sensitive topics. *Qualitative Health Research*, vol. 16, no. 6, pp. 853-871.

DICKSON-SWIFT, V., JAMES, E.L., KIPPEN, S. and LIAMPUTTONG, P., 2008. Risk to Researchers in Qualitative Research on Sensitive Topics: Issues and Strategies. *Qualitative Health Research*, vol. 18, no. 1, pp. 133-144.

DINESEN B, NOHR C, ANDERSEN SK, SEJERSEN H & TOFT E 2008. Under surveillance, yet looked after: telehomecare as viewed by patients and their spouse/partners. *European Journal of Cardiovascular Nursing*. vol.7, no.3, pp. 239-246.

DOWLING, M., 2006. Approaches to reflexivity in qualitative research *Nurse Researcher*, vol. 13 no.3.pp. 7-21.

DRIBBEN, M. and LEAN, M., 2003. Achieving compliance in chronic illness management: illustrations of trust relationships between physicians and nutrition clinic patients. *Health, Risk & Society*, vol,5.no.3, pp.241-259.

DUNCAN, E., BEST, C. and HAGEN, S., 2010. Shared decision making interventions for people with mental health conditions. *Cochrane Database of Systematic Reviews*. Issue 1, no. CD007297 [viewed 5<sup>th</sup> November 2103]. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20091628>

DUNCAN, R.E, DREW, S.E. and Sawyer, S.M., 2009. Is my mum going to hear this? Methodological and ethical challenges in qualitative health research with young people. *Social Science & Medicine*, vol. 69, no. 11, pp. 1691-1699.

DYSON, S. and BROWN, B., 2006. *Social theory and applied health research*. Glasgow: Open University Press.

EDWARDS, A. and ELWYN, G., 2009. *Shared Decision-Making in Health Care*. 2<sup>nd</sup> ed. Oxford: Oxford University Press.

EIDE, H., SIBBERN, T., EGELAND, T., FINSET, A., JOHANNESSEN, T., MIASKOWSKI, C. and RUSTOEN, T., 2011. Fibromyalgia patients' communication of cues and concerns: Interaction analysis of pain clinic consultations. *The Clinical Journal of Pain*, vol. 27, no. 7, pp. 602-610.

ELAND-DE-KOK, P., VAN OS-MEDENDORP, H., VERGOUWE-MEIJER, A., RUIJNZEEL-KOOMEN, C. and ROS, W., 2011 A systematic review of the effects of e-health on chronically ill patients. *Journal of Clinical Nursing*, vol. 20, no. 21/22 pp. 2997-3010

EMBREY, N., 2006. A concept-analysis of self-management in long-term conditions. *British Journal of Neuroscience Nursing*, vol. 2, no. 10, pp. 507-513.

ENTWISTLE, V.A., 2000. Supporting and resourcing treatment decision-making: some policy considerations 17. *Health Expectations*, 03, vol. 3, no. 1, pp. 77-85.

ENTWISTLE, V., 2002. Putting participation in the picture *Health Expectations*, vol. 5, no. 2, pp. 93-94.

ENTWISTLE, V., 2004. Trust and shared decision-making: an emerging research agenda 18. *Health Expectations*, 12, vol. 7, no. 4, pp. 271-273.

ENTWISTLE, V.A., 2006a. Considerations of 'fit' and patient involvement in decision making 7. *Health Expectations*, vol. 9, no. 2, pp. 95-97.

ENTWISTLE, V., 2006b. Which surgical decisions should patients participate in and how? Reflections on women's recollections of discussions about variants of hysterectomy. *Social Science & Medicine*, vol. 62, no. 2, pp. 499-509.

ENTWISTLE, V.A., 2010(a). Enabling consultations: the facilitative significance of relational aspects of interpersonal communication 10. *Health Expectations*, vol. 13, no. 1, pp. 1-3.

ENTWISTLE, V.A., 2010(b). Involving service users in qualitative analysis: approaches and assessment 13. *Health Expectations*, vol. 13, no. 2, pp. 111-112

ENTWISTLE, V.A., WATT, I.S., GILHOOLY, K., BUGGE, C., HAITES, N. and WALKER, A.E., 2004. Assessing patients' participation and quality of decision-making: insights from a study of routine practice in diverse settings *Patient Education & Counseling*, vol. 55, no. 1, pp. 105-113.

ENTWISTLE, V.A. and WATT, I.S., 2006. Patient involvement in treatment decision-making: the case for a broader conceptual framework 14. *Patient Education & Counselling*, vol. 63, no. 3, pp. 268-278.

ENTWISTLE, V., WILLIAMS, B., SKEA, Z., MACLENNAN, G. and BHATTACHARYA, S., 2006. Which surgical decisions should patients participate in and how? Reflections on women's recollections of discussions about variants of hysterectomy. *Social Science & Medicine*, vol. 62, no. 2, pp. 499-509.

ENTWISTLE, V., CALNAN, M. and DIEPPE, P., 2008a. Consumer involvement in setting the health services research agenda: persistent questions of value 8. *Journal of Health Services Research & Policy*, vol. 13, pp. 76-81.

ENTWISTLE, V., PRIOR, M., SKEA, Z.C. and FRANCIS, J.J., 2008b. Involvement in treatment decision-making: its meaning to people with diabetes and implications for conceptualisation 12. *Social Science & Medicine*, vol. 66, no. 2, pp. 362-375.

ENTWISTLE, V.A., Carter S.M., A, C. and McCaffery K., 2010. Supporting Patient Autonomy: The Importance of Clinician-patient Relationships. *Journal of General Internal Medicine*, vol. 25, no. 7, pp. 741-745.

ERICKSON, R.J. and GROVE W.J.C., 2008. Emotional Labour and Health Care. *Sociology Compass*, vol. 2, no. 2, pp. 704-733.

FINE, G.A., 1993. The sad demise, mysterious disappearance and glorious triumph of symbolic interactionism *Annual Review of Sociology*, vol. 19, pp.61-87.

FISCHER, M. and EREAUT, G., 2012. *When doctors and patients talk: making sense of the consultation*. London: The Health Foundation.

FLYVBJERG, B., 2006. Five misunderstandings about case study research. *Qualitative Inquiry*, vol. 12, no. 2, pp. 219-245.

FOSTER, G., TAYLOR, S.J., ELDRIDGE, S., RAMSAY, J. and GRIFFITHS, C.J., 2007. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews* [online] Issue 4 [Viewed 21<sup>st</sup> Sept 2010]. Available from:<http://web.ebscohost.com/ehost/detail?vid=1&hid=15&sid=8622d340-5dbb-4565-b2de98aed4f047a9%40sessionmgr11&bdata=JnNpdGU9ZWwhvc3QtbGl2ZQ%3d%3d#db=c8h&AN=2009825115>

FOX, J., 2005. Care of chronic conditions. The role of the expert patient in the management of chronic illness. *British Journal of Nursing*, vol. 14, no. 1, pp. 25-28.

FOX, J., 2008. Defining expertise by experience. *A Life in the Day*, 05, vol. 12, no. 2, pp. 17-20.

FOX, N.J. and O'Rourke, A.J., 2005. The "expert patient": empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the internet. *Social Science & Medicine*, vol. 60, pp. 1299-1309.

- FRANCIS, R., 2013. *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry*. London : HMSO.
- FRANK, A., 2000. Illness and autobiographical work. *Qualitative Sociology*, vol. 23, pp. 135-156.
- FRIEDSON, E., 1984. The changing nature of Professional Control. *Annual Review of Sociology*, vol. 10, pp. 1-20.
- FRIESE, C.R. and BECK, S.L., 2004. Advancing practice and research: creating evidence-based summaries on measuring nursing-sensitive patient outcomes *Clinical Journal of Oncology Nursing*, vol. 8, no.6, pp. 675-7.
- FURLONG, E. and SMITH, R., 2005. Advanced nursing practice: policy, education and role development. *Journal of Clinical Nursing*, vol. 14. no.9, pp.1059-1066.
- GABE, J., OLUMIDEB, G. and BURY, M., 2004. It takes three to tango, a framework for understanding patient partnership in paediatric clinics. *Social Science & Medicine*, vol. 59, no. 5, pp. 1071-1079.
- GALLAGHER, T.J., STANFORD, W.G., BIANCHI, A.J., HARTUNG, P.J. and HARKNESS, S., 2005. Examining Medical Interview Asymmetry using the Expectations States approach. *Sociology Psychology Quarterly*, vol. 68, no. 3, pp. 187-203.
- GALLANT, J.M., BEAULIEU, M.C. and CARNEVALE, F.A., 2002, Partnership: an analysis of the concept within the nurse-client relationship *Journal of Advanced Nursing*, vol. 40, no.2, pp.149-157.
- GERRISH, K. and LACEY, A., 2006. *The Research Process in Nursing*. 5th ed. Oxford: Blackwell.
- GJENGEDAL, E., RUSTEON, T., WAHL, A. and HANESTAD, B., 2003. Growing up and living with cystic fibrosis: everyday life and encounters with the health care and social services- a qualitative study. *Advances in Nursing Science*, vol. 26, no. 2, pp. 149-159.
- GLASER, B. and STRAUSS, A., 1968. *The Discovery of Grounded Theory*. New York: Aldine.
- GOFFMAN, E., 1959. *The Presentation of Self in Everyday Life*. Middlesex: Penguin.
- GOFFMAN, E., 1961. *Encounters*. Middlesex: Penguin.
- GOFFMAN, E., 1971. *Relations in public*. Middlesex: Penguin.

GOFFMAN, E., 1975. *Frame analysis: an essay on the organization of experience* . Harmondsworth: Penguin.

GOLDBECK, L. and BABKA, C., 2001. Development and evaluation of a multi-family psychoeducational program for cystic fibrosis. *Patient Education and Counseling*, vol. 44 no.2, pp. 187-92.

GOODMAN, B. and CLEMOW, R., 2008. *Nursing and working with other people*. Exeter: Learning Matters.

GORTZIS, L.G., 2009. e-Health: Are there expert patients out there? *Health Sociology Review*, Vol. 18, no.2, pp. 173-181.

GRAY, B. and SMITH, P., 2009. Emotional labour and the clinical settings of nursing care: The perspectives of nurses in East London. 46. *Nurse Education in Practice*, vol. 9, no. 4, pp. 253-261.

GREENHALGH, T., 2009. Patient and public involvement in chronic illness: beyond the expert patient *British Medical Journal*, vol. 338 no.1048, pp. 629-631.

GREENOP, D., GLENN, S., LEDSON, M. and WALSHAW, M., 2010. Self-care and cystic fibrosis: a review of research with adults. *Health and Social Care in the Community*, vol. 18, no. 6, pp. 653-661.

GREGORY, D., RUSSELL, C. K. and PHILLIPS, L. R., 1997. Beyond textual perfection: Transcribers as vulnerable persons. *Qualitative Health Research*, vol. 7, no 2, pp.294-300.

GRIFFITHS, C., FOSTER, G., RAMSAY, J., ELDRIDGE, S. and TAYLOR, S., 2007. How effective are expert patient (lay led) education programmes for chronic disease? *British Medical Journal*, vol. 334, pp. 1254-1256.

GRIFFITHS, P., SIMON, M., RICHARDSON, A. and CORNER, J., 2013. Is a larger specialist nurse workforce in cancer care associated with better patient experience? *Journal of Health Services Research and Policy*, vol. 18, no.2S, pp. 39 -46.

GRIX, J., 2001. *Demystifying Postgraduate Research*. Birmingham: University of Birmingham Press.

HALLER, D.M., SANCI, L., SAWYER, S. and PATTON G., 2008. Do young people's illness beliefs affect healthcare? A systematic review. *Journal of Adolescent Health*, vol.42, pp. 436-449.

HANKS, R.G. 2008. The Lived Experience of Advocacy. *Nursing Ethics*, vol.15, no.4, pp. 468-476.

HARDEN, J., SCOTT, S., BACKETT-MILBURN, K. and Jackson, S., 2000. "Can't talk won't talk?: Methodological issues in researching Children". *Sociological Research Online*, vol. 5, no. 2, [Viewed 23rd Sep 2013]. Available from: <http://www.socresonline.org.uk/5/2/harden.html>

HAYES, S.C., 2004. Acceptance and commitment therapy, relational frame theory, and the third wave of behavioural and cognitive therapies. *Behavior Therapy*, vol.39, pp. 639-665.

HENDERSON, S., 2003. Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing*, 07, vol. 12, no. 4, pp. 501-508.

HERITAGE, J. MAYNARD, W., 2006. Problems and prospects in the study of physician-patient interaction: 30 years of research. *Annual Review of Sociology*, vol. 32, no. 0, pp. 351-374.

HEWISON, A., 1995. Nurses' power in interactions with patients. *Journal of Advanced Nursing*, vol. 21, no. 1, pp. 75-82.

HIBBARD, J., 2009. Using Systematic Measurement to Target Consumer Activation Strategies, *Medical Care Research and Review*, vol, 66, no.1, Supp. 9s-27s.

HILL, L., 2011. *Managing emotions in research*. [Seminar]. CFRF Seminar series. Edinburgh, 5<sup>th</sup> Oct, University of Edinburgh.

HILL, E.A., SMITH, C.V. and HADDEN, B.W., 2013 Autonomy in the Obstetrician/Gynecologist-Patient Relationship as a Predictor of Patient Satisfaction. *Yale Journal of Biology and Medicine*, vol. 86, no.2, pp.179-188.

HOCHSCHILD, A.R., 1983. *Than managed heart: Commercialization of Human Feeling*. Berkeley, CA. California: University of California Press.

HODSON, M., 2000. Adults: in Hodson M.E, Geddes D.M eds. *Cystic Fibrosis*. 2<sup>nd</sup> ed. London: Hodder Arnold.

HOLMAN, H, and LORIG, K., 2000 Patients as partners in managing chronic disease: partnership is a prerequisite for effective and efficient healthcare. *British Medical Journal*, vol. 320, no.7234 pp.526-7.

HOLLOWAY, I. and FRESHWATER, D., 2007. *Narrative Research in Nursing*. Oxford: Blackwell.

HOLLOWAY, W. and JEFFERSON, T., 2000a. *Becoming qualitative researchers*. London: Sage.

HOLLOWAY, W. and JEFFERSON, T., 2000b. *Doing qualitative research differently*. London: Sage.

HOLLOWAY, I. and WHEELER, S., 2010 *Qualitative Research for Nurses*, 3<sup>rd</sup> ed. Chichester: Wiley-Blackwell.

HOLYOAKE, D., 2011. Is the doctor-nurse game being played? *Nursing Times*, vol. 107, no. 43, pp. 12-14.

HONEY, P. and MUMFORD, A., 2006. *Learning Styles Questionnaire*. Revised edition. Berks: Honey.

HOOK, M.L., 2006. Partnering with patients- a concept ready for action. *Journal of Advanced Nursing*, vol. 56, no. 2, pp. 133-143.

HORNE, R., WEINMAN, J., BARBER, N., ELLIOT, R. and MORGAN, M., 2005. *Concordance, adherence and compliance in medicine taking. Report for the national co-ordinating centre for NHS delivery and organisation R and D*. [online]. London: NCCSDO. [Viewed 17<sup>th</sup> October 2013]. Available from: [http://www.academia.edu/855004/Concordance Adherence and Compliance in Medicine Taking](http://www.academia.edu/855004/Concordance_Adherence_and_Compliance_in_Medicine_Taking).

HUBERT, D., LACARRIERE, C., PANZO, R., TOULORGE, C., CLAVEL, F. and DAVID, V., 2013. Improving communication between adults with cystic fibrosis and their CF physician. (ePoster) *Journal of Cystic Fibrosis*, 12: Suppl 1: WS11.3/S22:

IRWIN, L.G. and JOHNSON, J., 2005 Interviewing young children: Explicating our practices and dilemmas. *Qualitative Health Research*, vol. 15, pp. 821-831.

INTERNATIONAL COUNCIL OF NURSES (ICN)., 2002 Definition and characteristics of nurse practitioners/advanced practice nurses. *Practice Issues* [online]. [Viewed 12<sup>th</sup> October 2013]. Available from: <http://www.icn-apnetwork.org>

JASPER, M., 2006. Professional Development Reflection and decision-making. [Online] Oxford: Blackwell. [Viewed 14<sup>th</sup> October 2013]. Available from: <http://millennium.qmu.ac.uk/search~S0?/dreflection/dreflection/1%2C5%2C34%2CB/frame&FF=dreflection+philosophy&9%2C%2C22/indexsort=->

JOLLEY, J., 2006. Commentary on Coyne I (2006) Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*. 15, 61-71. *Journal of Clinical Nursing*, vol. 15, no. 6, pp. 785-789.

JONES, C. and LYONS, C., 2004. Case Study: Design? Method? Or comprehensive strategy? *Nurse Researcher*, vol. 11, no.3, pp. 70-76



- JOOTUN, D., MCGHEE, G. and MARLAND, G., 2009. Reflexivity: promoting rigour in qualitative research. *Nursing Standard*, vol. 23, no. 23, pp. 42-46.
- KANGAS, I., 2002. Health and Illness 'Lay' and 'Expert': Illness Knowledge Constructions in the Sociology of health and illness. *Health*, vol. 6, no. 3, pp. 301-304.
- KENNEDY, A., ROGERS, A. and GATELY, C., 2005. Assessing the introduction of the expert patients programme into the NHS: a realistic evaluation of recruitment to a national layed self-care initiative. *Primary Health Care Research and Development*, vol.6, no.2, pp. 137-148.
- KETTLER, L.J., SAWTER, S.M., WINEFIELD, H.R. and GREVILLE, H.W., 2002. Determinants of adherence in adults with cystic fibrosis. *Thorax*, vol.57, pp.459-464.
- KHAN, L.K., KLEIJNEN, J. and ANTES, G., 2003. *Systematic Reviews to support Evidence-Based Medicine: How to Review and Apply Findings of Health care Research*. London: Royal Society of Medicine press.
- KOCH, T., 2006. Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, vol. 53, no. 1, pp. 91-103.
- KOCH, T., JENKIN, P. and KRALIK, D., 2004. Chronic illness self-management: locating the 'self'. *Journal of Advanced Nursing*, 12, vol. 48, no. 5, pp. 484-492.
- KRALIK, D., PRICE, K. and TELFORD, K., 2010. The meaning of self-care for people with chronic illness. *Journal of Nursing and Healthcare of Chronic Illness*, vol. 2, no. 3, pp. 197-204.
- KRALIK, D., KOCH, T. WEBB, C., 2001. The domination of chronic illness research by biomedical interests. *Australian Journal of Holistic Nursing*, vol.8, no.2 pp.4-12.
- KUHN, M., 1964. Major trends in Symbolic Interactionism over the past twenty five years. *Sociological Quarterly*, vol.5, pp. 61-84.
- KURTZ, S., SILVERMAN, J. DRAPER, J., 2005. *Teaching and Learning Communication skills in medicine*. 2<sup>nd</sup> ed. Oxford: Radcliffe.
- KVALE, S., 1996. *Interviews. An introduction to qualitative research interviewing*. Thousand Oaks: Sage.
- LANDSBERGER, H.A., 1958. *Hawthorne Revisited*, Ithaca, New York.
- LANSLEY, A., 2010. *Andrew Lansley sets out his ambitions for the NHS*. [Viewed 1<sup>st</sup> Oct 2013]. Available: <http://www.andrewlansley.co.uk/newsevent.php?newseventid=136>

- LAU WALKER, M., 2004. Relationships between illness representation and self efficacy. *Journal of Advanced Nursing*, vol.48, no.3, pp. 216-225.
- LAWTON, J., 2003. Lay experiences of health and illness: past research and future agendas. *Sociology of Health & Illness*, vol. 25, pp. 23-40.
- LEE, P., 2007. What does partnership in care mean for children's nurses? *Journal of Clinical Nursing*, vol. 16, no.3, pp. 518-526.
- LEE, Y.Y. and LIN, J.L., 2010. Do patient autonomy preferences matter? Linking patient-centred care to patient-physician relationships and health outcomes. *Social Science and Medicine*, vol. 71, no. 10, pp. 1811-1818.
- LEE, Y. and LIN, J., 2011. How much does trust really matter? A study of the longitudinal effects of trust and decision-making preferences on diabetic patient outcomes. *Patient Education and Counselling*, vol.85, no.3, pp.406-12.
- LEGARD, R., KEEGAN, J. and WARD, K., 2003. In-depth Interviews. In: J. RITCHIE and J. LEWIS eds., *Qualitative Research Practice*, pp. 138-169. London: Sage.
- LESERMAN, J., IRONSON, G., O'CLEIRIGH, C., FORDIANI, J.M. and BALBIN, E., 2008. Stressful life events and adherence in HIV. *AIDS Patient Care and STDS*, vol. 22, no. 5, pp. 1-9.
- LEVINSON, W., GORAWARA-BHAT, R. and LAMB, J., 2000. A study of patient clues and physician responses in primary care and surgical settings. *Journal of the American Medical Association*, vol. 284, no. 8, pp. 1021-1027.
- LEWIN, S.A., SKEA, Z.C., ENTWISTLE, V.A., ZVARENSTEIN, M. and DICK, J., 2001. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews*, Issue 4, no. CD003267.
- LINCOLN, Y.S. and GUBA, E.G., 1985. *Naturalistic Inquiry*. Newbury Park, California: Sage.
- LINDSAY S., KINGSNORTH, S. and HAMDANI, Y., 2011. Barriers and facilitators of chronic illness self-management among adolescents: a review and future directions, *Journal of Nursing and HealthCare of Chronic Illness*, vol.3, pp.186-208.
- LOEWE, R., SCHWARTZMAN, J., FREEMAN, J., QUINN, L. and ZUCKERMAN, S., 1998. Doctor talk and diabetes: towards an analysis of the clinical construction of chronic illness. *Social Science & Medicine*, vol.47, no.9, pp. 1267-76.
- LORIG, K.R., SOBEL, D.S., STEWART, A.L., BROWN, J., BANDURA, A., RITTER, P., GONZALEZ, V.M., LAURENT, D.D. and HOLMAN, H.R., 1999. Evidence suggesting that a

chronic disease self-management program can improve health status while reducing hospitalization a randomized trial. *Medical Care*, vol.37, no.1, pp. 5-14.

LOVELL, B.L., LEE, R.T. and BROTHERIDGE, C.M., 2011. Interpersonal factors affecting communication in clinical consultations: Canadian physicians' perspectives. *International Journal of Health Care Quality Assurance*, vol. 25, no. 6, pp. 467-482.

LOWTON, K. and GABE, J., 2003. Life on a slippery slope: perceptions of health in adults with cystic fibrosis *Sociology of Health & Illness*, vol. 25, no.4,pp. 289-319.

LOWTON, K., 2006. Trials and tribulations: Understanding motivations for clinical research participation amongst adults with cystic fibrosis. *Social Science and Medicine*, vol. 61, no. 8, pp. 1854-1865.

LOWTON, K. and BALLARD K.D., 2006 Adult cystic fibrosis patients' experiences of primary care consultations: A qualitative study. *British Journal of General Practice*, vol. 56, no.528, pp. 518-525.

LTCAS 2008. *Gaun Yersel' The Self Management Strategy for Long Term Conditions in Scotland*. Scottish Government, [online]. Edinburgh. Available from: <http://www.scotland.gov.uk/Publications/2008/10/GaunYersel>, Accessed 10/9/10.

LTCC 2010 *Making the Connections- Food for thought*. Edinburgh: Scottish Government.

LUCK, L.,JACKSON, D. and USHER, K., 2006. Case study: a bridge across paradigms *Nursing Inquiry*, vol.13. no.2, pp.103-109.

MACDONALD, H., 2006. Relational ethics and advocacy in nursing: literature review. *Journal of Advanced Nursing*, vol.57, no.2, pp.119-126.

MACDONALD, K., 2009. The expert CF patient: reality or lip service? *Cystic Fibrosis Worldwide*, edition 12.

MACDONALD, K. and GREGGANS, A., 2008 dealing with chaos and complexity. *Journal of Clinical Nursing*, vol.17, no.23, pp.3123-3130.

MACDONALD, K. and GREGGANS, A., 2010. "Cool friends", *evaluation of a community youth befriending programme for young people with cystic fibrosis and their carers*. Edinburgh: QMU.

MACDONALD, K., 2013a. The Ceremonial Order of the Clinic: Time for a new model of Partnership? *Journal of Cystic Fibrosis*, 12 Suppl.1 S137.

- MACDONALD, K., 2013b. What strategies are used by young "expert patients" with cystic fibrosis to maintain and negotiate partnership? *Journal of Cystic Fibrosis*, 12 Suppl.1 S138.
- MACK, L., 2010. The Philosophical Underpinnings of Educational Research. *Polyglossia*, vol. 19, pp. 4-11.
- MACK, N., WOODSONG, C., MACQUEEN, K. and NAMEY, E., 2005. *Qualitative Research Methods: A data collector's field guide*. Carolina: USAID N.
- MADDISON, J. BERESFORD, B., 2012. The development of satisfaction with service-related choices for disabled young people with degenerative conditions : evidence from parents' accounts. *Health & Social Care in the Community*, vol. 20, no. 4, pp. 388-399.
- MANLEY, K., 1997 A conceptual framework for advanced practice: an action research project operationalizing an advanced practitioner/consultant nurse role. *Journal of Clinical Nursing*, vol. 6, no.3, pp.179-190.
- MANLEY, K. and GARBETT, R., 2000. Paying Peter and Paul; reconciling concepts of expertise with competence for a clinical career structure. *Journal of Clinical Nursing*, vol.9. pp. 347-359.
- MANLEY, K., HARDY, S., TITCHEN, A., GARBETT, R. and MCCORMACK, B. 2005. *Changing patient's worlds through nursing practice expertise*. London: RCN.
- MARINKER, M., BLENKINSOPP, A., BOND, C., BRITEN, N., FEELY, M., GEORGE, C., GREEN, P. HARRIS, C.M., HURST, L., MAGGS,C., McAVOY, P., McGAVOCK, H., NOYCE, P., ROWE, M.,TAYLOR, D.,TILLET,K.,WEINMAN,J. and YOUNG, J., 1997. eds. *From compliance to concordance: achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society of Great Britain.
- MASON, J., 2002. Qualitative Interviewing: Asking, Listening and Interpreting. In: T. MAY ed., *Qualitative Research in Action*. London: Sage, pp. 225-241.
- MAUTHNER, M., 1997. Methodological Aspects of Collecting Data from Children: Lessons from Three Research Projects. *Children & Society*, vol. 11, pp. 16-28.
- MAXWELL, J.A., 2005. *Qualitative Research Design*. 2nd ed. London: Sage.
- MAY, C., 1995. Patient autonomy and the politics of professional relationships. *Journal of Advanced Nursing*, vol. 21, pp. 83-87.
- MAY, C., 2006. Self-management of chronic conditions: re-engineering patient- hood. *Chronic Illness*, vol. 2, pp. 15-16.

- MAYNARD, D., HERITAGE, J., 2005. Conversation analysis, doctor-patient interaction and medical communication. 41. *Medical Education*, vol. 39, pp. 428-435.
- MAYOR, V., 2006. Long-term conditions. 3: being an expert patient. *British Journal of Community Nursing*, 02, vol. 11, no. 2, pp. 59-63.
- MAYS, N. and POPE, C., 2006. *Qualitative research in Healthcare*. 3<sup>rd</sup> ed. London: Blackwell.
- MCCLEAN, S. and SHAW, A., 2005. From Schism to Continuum? The Problematic Relationship Between Expert and Lay Knowledge—An Exploratory Conceptual Synthesis of Two Qualitative Studies. *Qualitative .Health Research*, vol. 15, no. 5, pp. 729-749.
- MCCONNELL-HENRY, T., CHAPMAN, Y. and FRANCIS, K., 2011. Member checking and Heideggerian phenomenology; a redundant component. *Nurse Researcher*, vol. 18, no. 2, pp. 28-37.
- MCCOSKER, H., BARNARD, A. and GERBER, R., 2001. Undertaking sensitive research: Issues and strategies for meeting the safety needs of all participants. . *Qualitative Social Research*, vol. 2, no. 1 [Viewed 10<sup>th</sup> September 2103]. Available from: <http://www.qualitative-research.net/fqs-texte/1-01/1-01mccoskeretal-e.pdf>.
- MCCULLOUGH, L.B., 2011. Was bioethics founded on historical and conceptual mistakes about medical paternalism? *Bioethics*, vol. 25 no.2, pp. 66-74.
- MCINTOSH, J. and RUNCIMAN, P., 2008. Exploring the role of partnership in the home care of children with special needs: Qualitative findings from two service evaluations. *International Journal of Nursing Studies*, vol.45, pp.714-726.
- MCKINLEY, T., 2011. Information Governance [Seminar] Edinburgh: Wellcome Trust Clinical Research Facility. 1<sup>st</sup> November.
- MCQUEEN, A., 2000. Nurse-patient relationships and partnership in hospital care. *Journal of Clinical Nursing*, vol. 9, no. 5, pp. 723-731. [viewed 23<sup>rd</sup> September 2013]. Available from: <http://dx.doi.org/10.1046/j.1365-2702.2000.00424.x>.
- MEAD, N. and BOWER, P., 2000a. Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine*, vol. 51, no. 7, pp. 1087-1110.
- MEAD, N. and BOWER, P., 2000b. Measuring patient-centredness: a comparison of three observation-based instruments. *Patient Education & Counselling*, vol.39, no.1, pp.71-80.

MEAD, N., BOWER, P. and Hann, M., 2002. The impact of general practitioners' patient-centredness on patients' post consultation satisfaction and enablement. *Social Science & Medicine*, vol.55, no.2, pp. 283-299.

MEICHENBAUM, D and TURK, D.C., 1987. Treatment adherence: terminology, incidence and conceptualization. In *Facilitating treatment adherence*. New York: Plenum Press.

MELLOR, N., 2001. Messy Method: the unfolding story. *Educational Action Research*, vol. 9, no. 3, pp. 464-484.

MIKESALL, L., 2013. Medicinal relationships: caring conversation. *Medical Education*, vol. 47, pp. 443-453.

MILES, M.B. and HUBERMAN, A.M., 1994 *Qualitative Data Analysis* 2<sup>nd</sup> ed. London: Sage.

MODI, A.C. and QUITTNER, A.L., 2006. Barriers to Treatment Adherence for Children with Cystic Fibrosis and Asthma: What Gets in the Way? *Journal of Pediatric Psychology*, vol. 31, no. 8, pp. 846-858.

MOORE, L. and KIRK, S., 2010. A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing*, vol. 19, no.15/16, pp.2215-2225.

MORAN-ELLIS, J.V., CRONIN, A., DICKINSON, M., FIELDING, J., SLENEY, J. and THOMAS, H., 2006. Triangulation and integration: processes, claims and implications. *Qualitative Research*, vol. 6, no. 1, pp. 45-59.

MORGAN, J. and KRONE, K., 2001. Bending the rules of "professional" display: Emotional Improvisation in caregiver performances. *Journal of Applied Communication Research*, vol. 29, no. 4, pp. 317-340.

MORSE, J.M., 1991. Negotiating commitment and involvement in the nurse--patient relationship. *Journal of Advanced Nursing*, vol. 16, no. Apr 91, pp. 455-68.

MORSE, J., 1994 *Critical Issues in Qualitative Research Methods*. Thousand Oaks, California: Sage.

MORSE, J.M., and FIELD, P.A., 1996. *Nursing Research*. Cheltenham: Nelson Thornes.

MUECKE, M., 1994. On the Evaluation of Ethnographies. In: J.M. MORSE ed., *Critical Issues in Qualitative Research Methods*. California: Sage.

MULHALL, A., 2003. In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*, vol. 41, no. 3, pp. 306-313.

NAUMANEN-TUOMELA, P., 2001. Concept analysis of expertise of occupational health nurses applying Rodger's evolutionary model. *International Journal of Nursing Studies*, vol. 7, pp. 257-265.

NEWBOULD, J., TAYLOR, D. and BURY, M., 2006. Lay-led self-management in chronic illness: a review of the evidence. *Chronic Illness*, vol.2, no.4,pp. 249-61.

NHS EDUCATION SCOTLAND, 2009. *Supporting People with Long-Term Conditions to Self Manage*. Edinburgh: South East Long Term Conditions Partnership Project.

NHS EDUCATION SCOTLAND. 2011. *Caldicott Guardians*. Viewed [14<sup>th</sup> October 2013]. Available from: <http://www.knowledge.scot.nhs.uk/caldicottguardians.aspx>.

NHS SCOTLAND 2003. *NHS Code of practice on protecting patient confidentiality*. Edinburgh: Scottish Executive. [Viewed 14<sup>th</sup> October 2013]. Available from: <http://www.ehealth.scot.nhs.uk/wp-content/documents/nhs-code-of-practice-on-protecting-patient-confidentiality.pdf>.

NHS RESEARCH AUTHORITY. 2013 *Scotland A Research Ethics Committee*. [Viewed 5<sup>th</sup> November 2013]. Available from: <http://www.nres.nhs.uk/applications/booking-and-submitting-your-application/nres-committee-directory/?entryid27=18663>

O'CONNOR, A.M., BENNETT, C.L., STACEY, D., BARRY, M., COL, N.F., EDEN, K.B., ENTWISTLE, V.A., FISET, V., HOLMES-ROVNER, M., KHANGURA, S., LLEWELLYN-THOMAS, H. and ROVNER, D., 2009. Decision aids for people facing health treatment or screening decisions (Review). *Cochrane Database of Systematic Reviews*, Issue 3. Art. No.: CD001431.

OLDE HARTMAN, T.C. and VAN RAVESTEIJN, H.J., 2008. "Well doctor, it is all about how life is lived: cues in the medical consultation. *Mental Health in Family Medicine*, vol. 5, pp. 183-187.

OVRETVEIT, J., 2012. *Do changes to patient-provider relationships improve quality and save money?* London: The Health Foundation.

PAI, A.L.H. OSTENDORF, H.M., 2011. Treatment Adherence in Adolescents and Young Adults Affected by Chronic Illness During the Health Care Transition From Pediatric to Adult Health Care: A Literature Review. *Children's Health Care*, vol. 40, pp. 16-33.

PARSONS, T., 1951. *The social system*. Chicago: Free Press.

PATERSON B. and THORNE, S. 2000. Expert Decision-making in relation to unanticipated blood glucose levels. *Research in Nursing and Health*, vol. 23, no.2, pp. 147-157.

- PATERSON, B. THORNE, S. and RUSSELL. C., 2002. Disease-specific influences on meaning and significance in self-care decision-making in chronic illness. *Canadian Journal of Nursing Research*, vol.34, no.3 pp. 61-74.
- PATTERSON, C. and HADDAD, B., 1992. The advanced nurse practitioner: common attributes. *Canadian Journal of Nursing Administration*, vol.5, no 4. pp.18-22.
- PATTON, M.Q., 2002. *Qualitative research and evaluation methods*. 3rd ed. Thousand Oaks: sage.
- PETERSEN, A. 2006. The best experts: The narratives of those who have a genetic condition. *Social Science & Medicine*, vol. 63, pp. 32-42.
- PIAGET, J., 1964. Part 1: Cognitive development in children: Piaget development and learning. *Journal of Research in Science Teaching*, no. 2, pp. 176-186.
- PILNICK, A. and DINGWALL, R., 2011. On the remarkable persistence of asymmetry in doctor/patient interaction: a critical review. *Social Science & Medicine*, vol. 72, pp. 1374-1382.
- PLAYLE, J.F. and KEELEY, P., 1998. Non-compliance and professional power. *Journal of Advanced Nursing*, vol. 27, pp. 304-311.
- POLIT, D.F. and BECK, C.T., 2004. *Nursing Research*. 7th ed. Lippincott: New York.
- POPE, C., ZIEBLAND, S. and MAYS, N., 2000. Analysing Qualitative Data. *British Medical Journal*, vol. 320, pp. 214.
- PRIOR, L., 2003. Belief, knowledge and expertise: The emergence of the lay expert in medical sociology. *Sociology of Health and Illness*, vol. 25, no. 1, pp. 41-57.
- PROCTOR, S., 1998. Linking philosophy and method in the research process: the case for realism. *Nurse Researcher*, no. 5, pp. 73-90.
- PROCTOR, S. and ALLAN, T., 2006. Sampling. In: K. GERRISH and A. LACEY eds. *The Research Process in Nursing*. 5th ed. Oxford: Blackwell, pp. 173-188.
- PRUITT, R.H. and PRIVETTE, A.B., 2001. Planning strategies for the avoidance of pitfalls in intervention research. *Journal of Advanced Nursing*, vol. 35, no. 4, pp. 541-520.
- PUBLIC HEALTH RESOURCE UNIT (PHRU) 2006. *CRITICAL APPRAISAL SKILLS PROGRAMME* (CASP) [Online]. Available from: <http://www.casp-uk.net/> Viewed 27<sup>th</sup> August 2013.



QSR International., 2012. *NVivo 9.2.[Online]*. Available from: <http://www.qsrinternational.com/about-qsr.aspx>. Viewed 10th July 2013.

QUEEN MARGARET UNIVESITY, 2010. *Revised Research Ethics Guidelines* Available from: <http://intranet.qmu.ac.uk/sites/researchEthicsPanel/default.aspx> Viewed 31st March 2011.

RAYNOR, D.K., THISTLETHWAITE, J.E., HART, K. and KNAPP, P., 2001. Are health professionals ready for the new philosophy of concordance in medicine? *International Journal of Pharmacy Practice*, vol. 9, pp. 810-84.

REEVES, S., KUPER, A. and HODGES, B.D., 2008a. Qualitative Research Methodologies: ethnography. *British Medical Journal*, vol. 30, no. 337, pp. 1020.

REEVES, S., NELSON, S. and ZWARENSTEIN, M., 2008b. The doctor-nurse game in the age of interprofessional care: a view from Canada. *Nursing Inquiry*, vol. 15, no. 1, pp. 1-2.

RICHARDSON, L., 2000. Writing: a method of Inquiry. In: DENZIN, N. and LINCOLN, Y., 2000. eds. *Handbook of Qualitative Research*. 2nd ed. Thousand Oaks: Sage, pp. 923-949.

RITCHIE, J. and SPENCER, L., 1994. Qualitative data analysis for applied policy research. In: BRYMAN, A. and BURGESS, R.G. eds. *Analysing qualitative data*. London: Routledge, pp. 173-194.

RITCHIE, J. LEWIS, J., 2003. eds. *Qualitative Research Practice*. London: Sage.

ROBERTS, T., 2009. Understanding ethnography. *British Journal of Midwifery*, vol. 17, no. 5, pp. 291-294.

ROGERS A. 2009 Advancing the expert patient? *Primary Health Care Research & Development*, 10, 167-176.

ROGERS, A., KENNEDY, A., BOWER, P., GARDNER, C., GATELY, C., LEE, V., REEVES, D. and RICHARDSON, G., 2008. The United Kingdom Expert Patients Programme: results and implications from a national evaluation. *The Medical Journal of Australia*, vol. 189, no. 10 (supp), pp. 21-24.

ROGERS, A., KIRK, S., GATELY, C., MAY, C. and FINCH, T., 2011. Established users and the making of telecare work in long term condition management: implications for health policy. *Social Science & Medicine*, vol. 72, no.7.pp.1077-1084.

ROLFE, G., 2006. Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing*, vol. 53, no. 3, pp. 304-310.

ROYAL COLLEGE OF NURSING, 2010. *Specialist nurses changing lives saving money*. London: RCN.

RUSSELL, S., DALY, J., HUGHES, E. and OPT' HOOG, C., 2003. Nurses and "difficult" patients: negotiating non-compliance. *Journal of Advanced Nursing*, vol. 43, no. 3, pp. 281-287.

RUTTER, D., MANLEY, C., WEAVER, T., CRAWFORD, M. and FULOP, N., 2004. Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, vol. 58, no. 10, pp.1973–1984.

SACKETT D.L. WENNERBERG, J.E., 1997 (Editorial) Choosing the best research design for each question *British Medical Journal*,. vol. 315, pp. 1636.

SANDELOWSKI, M., 2000. Whatever happened to qualitative description? *Research in Nursing & Health*, vol.23, no.4, pp.334-340.

SALMON, P., DOWRICK, C.F., RING, A. and HUMPHRIES, G.M., 2004. Voiced but unheard agendas; qualitative analysis of the psychosocial cues that patients with unexplained symptoms present to general practitioners. *British Journal of General Practice*, vol. 54, pp. 171-176.

SANG, B., 2004. Choice, participation and accountability: assessing the potential impact of legislation promoting patient and public involvement in health in the UK. *Health Expectations*, 09, vol. 7, no. 3, pp. 187-190.

SANG, B., 2009. Personalisation: consumer power or social co-production. *Journal of Integrated Care*, 08, vol. 17, no. 4, pp. 31-38.

SAVAGE, E., BEIRNE, P.V., NI CHROININ, M., DUFF, A., FITZGERALD, T. and FARRELL, D., 2011. Self-management education for cystic fibrosis. *Cochrane Database of Systematic Reviews*, no. 7, Art. No. CD007641

SAWYER, S., DREW, S. and YEO, M.,2007 Adolescent health: adolescents with a chronic condition: challenges living, challenges treating. *Lancet*, vol.369, pp.1481-1489.

SAWICKI, G.S., SELLERS, D.E. and ROBINSON, W.M., 2008. High treatment burden in adults with cystic fibrosis: challenges to disease self-management. *Journal of Cystic Fibrosis*, vol. 8, no. 2, pp. 91-96.

SCOTTISH CENTRE FOR TELEHEALTH AND TELECARE. 2013. [Viewed 5<sup>TH</sup> November 2013]. Available from: <http://www.sctt.scot.nhs.uk/>

SCOTTISH GOVERNMENT, 2003. *NHS Scotland Code of Practice on Confidentiality*. Edinburgh: Scottish Government.

SCOTTISH EXECUTIVE, 2007. *Better Health Better Care*. Scottish Executive, Edinburgh.

SCOTTISH GOVERNMENT, 2010(a). *Anticipatory Care, Self- Management and Community – Led health improvement approaches for people with long term conditions*. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2010(b). *The Healthcare Quality Strategy for NHS Scotland*. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2011. *Better Together Sharing the learning; Report from the Better Together Long Term Conditions Workstream*. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2012(a). *Long Term conditions*. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2012(b). *20/20 Vision*. Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2013. *Route map to the 20/20 vision for health and social care*. Edinburgh: Scottish Government.

SEERS, K. 2012. Research made simple: Qualitative data analysis *Evidence Based Nursing* [Online] vol.15, Issue 1. [viewed 17<sup>th</sup> October 2010] Available from: <http://ebn.bmj.com/content/15/1/2.full>.

SHAW, J. and BAKER, M., 2004. "Expert patient" Dream or Nightmare? *British Medical Journal* [Online]. vol.328, no.723, Available from: <http://www.bmj.com/content/328/7442/723.full> Accessed 29th September 2010.

SHAW, S.M., 2007. Responding appropriately to patients with chronic illnesses. *Nursing Standard*, vol. 21, no. 24, pp. 35-39.

SILVERMAN, D., 2005. *Doing Qualitative Research*. 2nd ed. London: Sage.

SILVERMAN, D., KURTZ, S.M. and DRAPER, J., 2005. *Skills for communicating with patients*. 2<sup>nd</sup> ed. Milton Keynes: Radcliffe.

SILVERMAN, J., 2007. The Calgary-Cambridge Guides; The teenage years. *The Clinical Teacher*, vol. 4, pp. 87-93.

SIMON, G., VONKORFF, M., RUTTER, C. and WAGNER, E., 2000. Randomised trial of monitoring, feedback, and management of care by telephone to improve treatment of depression in primary care. *British Medical Journal*, vol.320, pp.550-554.

SKIRBECK, H. (2009). Presupposed or negotiated trust? Explicit & implicit interpretations of trust in a medical setting. *Medicine, Health Care & Philosophy*, vol.12, no.1, pp.3-7.

SKIRBECK, H., MIDDLETHON, A.L., HJORTDAHL, P. and FINSET, A., 2011. Mandates of trust in the Doctor-Patient relationship. *Qualitative Health Research*, vol, 21, no.9, pp.1182-1190.

SKUKAUSKAITE, A., 2012. Transparency in transcribing: Making visible theoretical bases impacting knowledge construction from open-ended interview records. *Qualitative Social Research*, vol. 13, no.1, Art.14

SMITH, P., 1992. *The Emotional Labour of Nursing*. Palgrave, Basingstoke: Palgrave Macmillan.

SMITH, P., 2007. Emotional labour: just another buzz word? *International Journal of Nursing Studies*, vol.44, pp. 851-854.

SMITH, J. and FRITH, J., 2011. Qualitative data analysis: the framework approach. *Nurse Researcher*, vol.18, no.2, pp.52-62.

SMITH, J., BECKKER, H. and CHEATER, F., 2011. Theoretical versus pragmatic design in qualitative research, *Qualitative Nurse Researcher*, vol.18, no.2, pp.39-51.

SNAPE, D. and SPENCER, L., 2003. *The Foundations of Qualitative Research*, in Ritchie J. and Lewis J (Eds) *Qualitative Research Practice*. London Sage.

SPENCER, L., RITCHIE, J. and O'CONNOR, W., 2003. Analysis: Practices, Principles and Processes. In: J. RITCHIE and J. LEWIS eds., *Qualitative Research Practice*. London: Sage, pp. 199-218.

SPEZIALE, H.J. and CARPENTER D.R., 2007. *Qualitative Research in Nursing*. 4<sup>th</sup> ed. Philadelphia: Lippincott, Williams & Wilkins.

SRIVASTAVA, N., TUCKER, J.S., DRAPER, E.S. and MILNER, M., 2008. A literature review of principles and practices in extended nursing roles related to UK intensive care settings. *Journal of Clinical Nursing*, vol.17, no.20, pp. 2671-2680.

STAKE, R., 1995. *The art of Case Study Research*. London: Sage.

STEIN, L.I., WATTS, D.T. and HOWELL, T., 1990. The doctor-nurse game revisited. *Nursing Outlook*, vol. 38, no. 6, pp. 264-268.

STEIN, L.I., 1967. 'The Doctor-Nurse Game', *Archives of General Psychiatry*, vol. 16, no. 6, pp. 699-703.

STEVENSON, F.A., BARRY, C.A., BRITTEN, N., BARBER, N. and BRADLEY, C.P., 2000. Doctor-patient communication about drugs: the evidence for shared decision making. *Social Science & Medicine*, vol. 50, no. 6, pp. 829-840.

STIMSON, G. and WEBB, B., 1975. *Going to see the doctor*. London: Routledge.

STOCKWELL, F., 1972. *The Unpopular Patient* RCN Research Project series 1 (2), London: RCN.

STODDART, K. and BUGGE, C., 2012. Uncovering the features of negotiation in developing the patient-nurse relationship. *British Journal of Community Nursing*, vol. 17, no. 2, pp. 77-84.

STRAUSS, A. and GLASER, B., 1975. *Chronic Illness and the quality of life*. St Louis: Mosby.

STRAUSS, A. and CORBIN, J., 1990. *Basics of qualitative research: grounded theory procedures and techniques*. California: Sage.

STRONG, P.M., 1979. *The Ceremonial Order of the Clinic Parents, Doctors and Medical Bureaucracies*. London: Routledge & Keegan Paul.

SUTTON, F. and SMITH, C., 1995. Advanced nursing practice: new ideas and new perspectives. *Journal of Advanced Nursing*, vol. 21, no. 6, pp. 1037-1043.

SWANBORN, P., 2010. *Case Study Research*. London: Sage.

TAYLOR, D. BURY, M., 2007. Chronic Illness, Expert patients and care transition. *Sociology of Health & Illness*, vol. 29, no. 1, pp. 27-45.

TAYLOR, R.M., GIBSON, F. and Franck, L., 2008 The experience of living with a chronic illness during adolescence: a critical review of the literature *Journal of Clinical Nursing*, vol. 17 no. 23, pp. 3083-3091.

THE SHIPMAN ENQUIRY., 2002. *Death Disguised 3*. HMSO.

THORNE, S., 1988. Reciprocal trust in health care relationships. *Journal of Advanced Nursing*, vol. 13, no. 6, pp. 782-789.

THORNE, S. and ROBINSON, C., 1989. Guarded alliance: Health care relationships in chronic illness. *Image: Journal of Nursing Scholarship*, vol. 21, pp. 153-157.

THORNE, S., 1993 *Negotiating Health Care*. London: Sage.

THORNE, S, KIRKHAM, S.R. and MACDONALD, E.J., 1997 Interpretive Description: a non categorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, vol. 20, no.2, pp169-177.

THORNE, S. and PATERSON, B., 1998. Shifting images of chronic illness. *Image: Journal of Nursing Scholarship*, vol. 30, no. 2, pp. 173-178.

THORNE, S. and HENDERSON, D., 1999. Are egalitarian relationships a desirable ideal in nursing? *Western Journal of Nursing Research*, vol.21 no.1, pp. 16-34

THORNE, S. E., TERNULF NYHLIN, K. and PATERSON, B. L., 2000. Attitudes toward patient expertise in chronic illness. *International Journal of Nursing Studies*, vol.37, no 4, pp.303-311.

TILLEY, S.A., 2003. "Challenging" research practices,: Turning a critical lens on the work of transcription. *Qualitative Inquiry*, vol. 9, no. 5, pp. 750-773.

TIMMINS, F. and MCCABE C., (2005) How to conduct an effective literature search. *Nursing Standard*, vol, 20, no,11, pp.41-47.

TIMMINS, F. and TANNER, J., 2005. Operating theatre Nurses:Emotional labour and the hostess role. *International Journal of Nursing Practice*, vol 11, pp. 85-91.

TOPPING, A., 2006. The Quantitative-Qualitative continuum in GERRISH, K. and LACEY, A., eds. *The Research Process in Nursing*. pp.129-141. Sussex: Wiley

TOWNSEND, A., WYKE, S. and HUNT, K., 2006. Self-managing and managing self: practical and moral dilemmas in accounts of living with chronic illness. *Chronic Illness*, vol. 2, no. 3, pp. 185-194.

TUCKETT, D., BOULTON, M., OULSON, C. and WILLIAMS, A., 1985. *Meetings Between Experts*. London: Tavistock.

TYREMAN, S., 2005a An expert in what?: The need to clarify meaning and expectations in "The Expert Patient" *Medicine and Health Care Philosophy*, vol. 8, pp.153-157.

TYREMAN, S., 2005b. The expert patient: outline of UK government paper. *Medicine and Health Care philosophy*, vol. 8, no.2, pp.149-51.

UK CF Registry, 2013. *Annual Data Report* : 2011 Kent: CF Trust.

UNICEF 1992. *United Nations Convention on the Rights of the Child* (UNCRC). Available from: [Viewed 28<sup>th</sup> August 2013].

<http://webarchive.nationalarchives.gov.uk/20100415085344/http://dcsf.gov.uk/everychildmatters/strategy/strategyandgovernance/uncrc/unitednationsconventionontherightsofthechild/>

VAN DER VEGTE, K., BREMER-OPHORST, I., AUFENACKER-VAN, S., BETHLEHEM, L., SEGERS, B. A. and VAN GEELLEN, S., 2013. What is it like to be an adolescent with cystic fibrosis? Reversing the roles of patient and health-professional. *Journal of Cystic Fibrosis*, vol. 12 Suppl. 1. S134.

VAN TEIJLINGEN, E.R. and HUNDLEY, V., 2001. *The Importance of Pilot Studies*. Guildford: University of Surrey.

WAITZKIN, H., 1991. *The politics of medical encounters*. New Haven: Yale University Press.

WALKER, C., 2001. Recognising the changing boundaries of illness in defining terms of chronic illness: a prelude to understanding the changing needs of people with chronic illness. *Australian Health Review*, vol. 24, no. 2.

WALLACE, L.M., TURNER, A., KOSMALA-ANDERSON, J., JESUTHASAN, J., BOURNE, C. and REALPE, A., 2012. Co-creating Health: Evaluation of the first phase. London: Health Foundation. [viewed 29<sup>th</sup> November 2013]. Available from: [http://www.health.org.uk/publications/?keywords=&refData\\_44=&refData\\_53=3060&searchSubmit=Go&siid=60](http://www.health.org.uk/publications/?keywords=&refData_44=&refData_53=3060&searchSubmit=Go&siid=60)

WALTERS, S., BRITTON, J. and HODSON, M.E., 1993. Demographic and social characteristics of adults with cystic fibrosis in the United Kingdom. *British Medical Journal*. vol. 306, no. 6877, pp. 549–552.

WANLESS, D., 2004. *Securing good health for the whole population*. Norwich: HMSO.

WATERWORTH, S., LUKER, K. 1990. Reluctant collaborators: Do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing*, vol. 15, no. 8, pp. 971.

WATSON, R., ATKINSON, I. and ROSE, K., 2007. Pilot Studies; to publish or not? *Journal of Clinical Nursing*, vol. 16, no. 4, pp. 619–620.

WEAVER, K. and OLSON, J.K., 2006. Understanding paradigms used for nursing research. *Journal of Advanced Nursing*, vol. 53, no. 4, pp. 459–469.

WELFORD, C., MURPHY, K. and CASEY, D., 2011. Demystifying nursing research terminology. Part 1. *Nurse Researcher*, vol. 18, no. 4, pp. 38–43.

WELLARD, S., 1998. Constructions of chronic illness. *International Journal of Nursing Studies*, vol.35, no.1/2, pp. 49-55.

WHITE, E., 2012. Challenges that may arise when conducting real-life nursing research. *Nurse Researcher*, vol. 19, no. 4, pp. 15-20.

WHITE, T., MILLER, J., SMITH, G.L. and MCMAHON, W.M., Adherence and psychopathology in children and adolescents with cystic fibrosis. *European Child Adolescent Psychology*, vol. 18, no.2, pp.96-104.

WHO., 2003. *Adherence to Long Term Therapies: Evidence for action*. WHO.[Viewed 29th August 2013]. Available from:  
<http://apps.who.int/medicinedocs/en/d/Js4883e/6.html>

WHO., 2008. *The World Health Report*. Geneva: WHO.

WHO., 2011. *Standards and Operational Guidance for Ethics Review of Health-Related Research with Human Participants*. Geneva: WHO.

WILDE, M.H. and GARVIN, S., 2007. A concept analysis of self-monitoring. *Journal of Advanced Nursing*, vol. 57, no. 3, pp. 339-350.

WILLIAMS, B., CORLETT, J., DOWELL, J. S., COYLE, J. and MUKHOPADHYAY, S., 2009. "I've never not had it so I don't really know what it's like not to": Nondifference and biographical disruption among children and young people with cystic fibrosis. *Qualitative Health Research*, vol.19, no.10, pp.1443-1455.

WILSON, H.V., 2001. Power and partnership: a critical analysis of the surveillance discourses of child health nurses. *Journal of Advanced Nursing*, vol.36, no.2, pp.294-301.

WILSON, J.H., 2009. *Self-management and Self-efficacy across the MS Journey*. PhD Thesis ed. Northumbria University.

WILSON, P.M., 2001. A Policy analysis of the Expert Patient in the United Kingdom: self-care as an expression of pastoral power? *Health and Social Care in the Community*, vol. 93, no. 3, pp. 134-142.

WILSON, P.M., 2005. Long-term conditions: making sense of the current policy agenda. *British Journal of Community Nursing*, 12, vol. 10, no. 12, pp. 544.

WILSON, P.M. MAYOR, V., 2006. Long-term conditions. 2: supporting and enabling self-care. *British Journal of Community Nursing*, vol. 11, no. 1, pp. 6-10.



WILSON, P.M., KENDAL, I.S. and BROOKS, F., 2006. Nurses' responses to expert patients: the rhetoric and reality of self-management in long term conditions: A grounded theory study. *International Journal of Nursing Studies*, vol. 43, pp. 803-818.

WILSON, P.M., 2007. *The Expert Patient: An Exploration of self-Management in Long Term Conditions*. PhD thesis ed. University of Hertfordshire.

WIRST, V., CRIBB, A. and BARBER, N., 2006. Patient-doctor decision-making about treatment within the consultation-A critical analysis of models. *Social Science & Medicine*, no. 62, pp. 116-124.

WOODGATE, R., 2001. Adopting the Qualitative Paradigm to understanding Children's Perspectives of illness: Barrier or Facilitator *Journal of Pediatric Nursing*, vol. 16, no.3, pp. 149-161.

WOOLCOT, H., 2002. Writing up Qualitative Research ... Better. *Qualitative Health Research*, vol. 12, no. 1, pp. 91-103.

WUEST, J., and STERN, P.N., 1990. The impact of fluctuating relationships with the Canadian health care system on family management of otitis media with effusion. *Journal of Advanced Nursing*, vol.15, no.5, pp.556-563.

YIN, R.K., 2009. *Case study Research*. 4th ed. London: Sage.

ZOMORODI, M. and FOLEY, B.J. 2009. The nature of "advocacy" vs "paternalism" in nursing: clarifying the "thin line" *Journal of Advanced Nursing*, vol. 65, no.8, pp. 1746-1752.

## **APPENDICES**

### **Appendix 1: Definition and critique of common terms used in the thesis**

#### **Compliance/Adherence/Concordance:**

##### **Compliance:**

"The extent to which patients are obedient and follow the instructions, proscriptions, and prescriptions of health care professionals", (Meichenbaum and Turk 1987 p.72)

##### **Adherence:**

"The extent to which a person's behaviour-taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health-care provider" (WHO 2003,p17).

##### **Concordance:**

"Agreement between the patient and healthcare professional, reached after negotiation that respects the beliefs and wishes of the patient in determining whether, when and how their medicine is taken, and (in which) the primacy of the patient's decision (is recognized)" (Marinker et al 1997, p12)."

Kettler et al. (2002) suggest that the first two terms are used interchangeably in the literature, and are rooted in a historical basis of benign paternalism (Marinker et al 1997). However, Kettler et al. (2002) assert that whilst adherence is viewed as a more engaging active process than compliance, neither definition assists with defining the criteria for compliance or adherence. i.e. at what point along the continuum from non-compliant/adherent to fully compliant/adherent is one considered compliant or adherent, as not all treatments require 100% adherence to affect a desirable outcome. The term concordance is said to be less judgemental than the former two as non-concordant refers to the consultation and not the patient (Marinker et al. 1997). The authors also argue that concordance reflects contemporary concepts of involvement and openness in relation to health care. However they stress that concordance comes with a price of increased patient responsibility for the choices made.

## **Paternalism**

Paternalism is said to be

“The intentional overriding of one person’s preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefitting or of preventing or mitigating harm to the person whose preferences or actions are overridden”

(Beauchamp and Childress 2009, p 208).

The term is also subject to much debate in the literature. Edwards and Elwyn (2009) suggest that the term is associated with dominant doctors and passive patients (citing Roter and Hall 1992) but assert that this assumption is flawed, as it characterises patients as rational actors in the medical consultation, who can make decisions with an absence of emotion. McCullough (2011) concurs with this view that assumes patients make decisions based on the same rationale as physicians, as opposed to inclination. Paternalism is also said to be driven historically by the Hippocratic Oath but McCullough (2011) refutes that there is sufficient historical or conceptual evidence to support this. Further, it is asserted that by asking doctors to discard paternalism in favour of respect for patient autonomy, Beauchamp and Childress (2009) may be asking physicians to respect patient decisions that may violate their duties to patients to preserve their life and health. This creates tensions with the principles of beneficence, maleficence and justice (McCullough 2011).

Zomorodi and Foley (2009) assert that there is a thin line between advocacy and paternalism especially when patients are silent, unable to communicate, not in receipt of all the facts in order to make an informed decision or not capable of doing so.

## **Self-Management**

Self-management is defined as

“The successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real

implications of living the rest of their life with one or more long term condition” (LTCAS 2008).

Embrey (2006) claims self-management is an ill-defined concept which is often advocated as effective in the management of long term conditions. Claims have been made as to the benefits of self-management in terms of reduced use of resources, increased self-confidence and self-efficacy and improved symptom control. However, the evidence to support this remains inconclusive and studies have been criticised for their methodological weaknesses and lack of long-term evaluation, (Foster et al. 2007, Wilson 2007, Rogers 2009, Coster and Norman 2009, Greenhalgh 2009). A further criticism of self-management is that outcomes are measured in professional rather than patient terms, with more emphasis placed on biomedical outcomes as viewed by professionals, compared to subjective improvement by patients (Newbould et al. 2006, Rogers 2009). The above definition which was constructed by people living with a long-term condition, was favoured as it does not attempt to define success or outcomes, thus it is assumed that they are defined by individuals’ own perceptions.

### **The expert patient**

The expert patient is defined as

“People who have the confidence, skills information and knowledge to play a central role in the management of life with chronic disease” DoH (2001).

A fuller debate regarding the concept of the expert patient can be found on p29.

### **Partnership:**

“An interpersonal relationship between two or more people who work together towards a mutually defined purpose” (Gallant et al. 2002).

A fuller debate on the concept of partnership can be found on pages 34-41.

## APPENDIX 2: CASP Appraisal Tool



### 10 questions to help you make sense of qualitative research

#### How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.

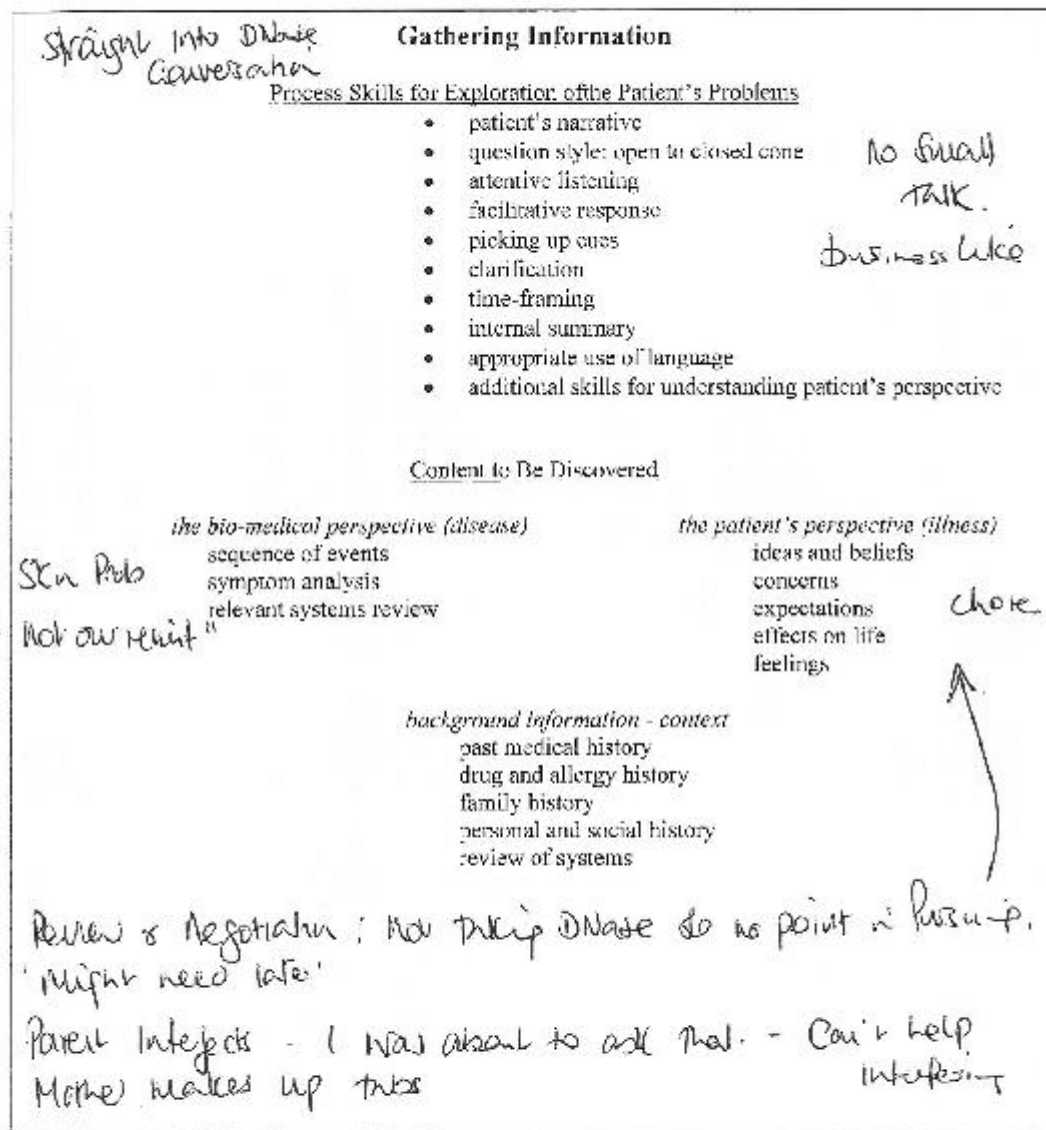
There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

There will not be time in the small groups to answer them all in detail!

©CASP This work is licensed under the Creative Commons Attribution - NonCommercial-ShareAlike 3.0 Unported License. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/3.0/> www.casp-uk.net

## APPENDIX 3: Calgary – Cambridge Guide

### Appendix 3: Calgary - Cambridge Guide



Dr - Anything you want to ask me?

#### **Appendix 4: Topic Guide for Interviews Version 2: 8/8/11**

1. Explore understanding of partnership? (prompts: context- how well do they know and trust each other, equality, power, knowledge, shared decision making, stages of partnership, involvement, respect autonomy (ethical frameworks). Is it different with this group, how?  
Have power bases changed in favour of pts over time how/why?
2. Barriers/enablers to partnership? (prompts: gender, age, experience (staff) role (staff), status, knowledge, personalities, styles of consultation, agendas, willingness to engage (pt, staff), willingness to negotiate, time, not wanting to lose them?
3. Negotiation- how are decisions negotiated? (Prompts; agendas, expectations of consultation, Cues why don't they ask?  
consequences, ? emotional labour, social v's biomedical constructions, what are patients priorities, what are HCP's priorities?, is there consistency across HCP's/pts or are styles adapted to suit the interaction? (Goffman) . preferred pts/hcp's why, who are they?
4. Explore understanding of expert patient? Views on expertise? (Prompts: is it about experience, knowledge, wisdom, engagement, intuition, language, technical aspects, anything else?)
5. Examples of experiences of successful/unsuccessful partnership working?
6. Consequences of successful/unsuccessful partnership working-  
perceived/experiential?  
prompts costs to each party- physical/ emotional, satisfaction, better health ,  
quicker/easier consultation/get out quicker (staff/pt)
7. Ceremonial order of the clinic, ritualisation, biomedical orientation. Repetition, thoughts and ideas for change if any?

## APPENDIX 5: Recruitment poster for potential participants



Queen Margaret University  
EDINBURGH

### HELP WANTED

Are you between 16- 35 years old?

Do you have CF?

Have you had this condition for 5 years or more?

Have you been a patient at the same specialist clinic for over a year?

Do you self manage your treatments and monitor the effects? (e.g. Insulin, IV's, nebulisers).

Do you visit a clinic at least 6 monthly to see a doctor, nurse, or other health professional?

If so I would like to invite you to participate in a research study.

My name is Kath MacDonald and I am a researcher who is interested in exploring the



way that experienced patients and health professionals work together. The research would involve observing a clinical consultation (with you your doctor or nurse) and having a chat about it afterwards.

If you would be interested in helping me please take one of the leaflets available at clinic or contact me on: 07988958549 or [kmacdonald@qmu.ac.uk](mailto:kmacdonald@qmu.ac.uk)





Queen Margaret University  
EDINBURGH

## **Participant Information Sheet**

### **Exploring interactions between young expert patients and health care professionals.**

**You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.**

#### **What is the purpose of the study?**

The purpose of the study is to explore the interactions between young people like you with a long term condition (like CF or Diabetes) and the Health care professionals (e.g. Doctors, nurses, dieticians) you meet with in order to manage your condition.

#### **Why have I been asked to take part?**

You have been asked to take part as you have been previously diagnosed with CF or Diabetes and attend a clinic, as part of your care.

#### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive.

#### **What will happen if I take part?**

A researcher will talk to you about your experiences of having a long term condition and the way that you and the health care professionals you see work together to manage it. The researcher would also like to sit in and observe the interactions between you and a professional during one of your clinic or GP visits.

So that the researcher does not miss any important details, she would like to audio tape the interview and the clinic consultation.

**What are the possible benefits of taking part?**

You may/may not get a direct benefit from taking part in this study. However the results of this study may help inform future developments in patient care.

**What are the possible disadvantages and risks of taking part?**

It is not thought that there are many disadvantages; however, it is possible that you would not wish anyone to sit in on your private consultation. This is your right. If you would still like to talk to the researcher about your interactions with professionals then we can just talk to you without being at your clinic/GP visit. The interview will last between 30 -45 mins at a place convenient to you.

**What happens when the study is finished?**

At the end of the research we will write a report and may publish the findings in conference reports or nursing Journals. You may be contacted when the research is in the final stages to confirm that the information you gave is a fair description of your views.

**Will my taking part in the study be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Your name and any place names will be removed from the data so that you cannot be recognised from it.

With your consent we will inform your GP that you are taking part.

**Who is organising the research and why?**

This study has been organised as part of a Doctoral degree through Queen Margaret University and has been given ethical approval by their ethics committee.

**Who has reviewed the study?**

The study proposal has been reviewed by NHS Research Ethics. A favourable ethical opinion has been obtained from South East Scotland Research Ethics Committee. NHS management approval has also been obtained.

**If you have any further questions about the study please contact Kath MacDonald on: 0131 474 0000 (automated system- ask for Kath MacDonald) or email: [kmacdonald@qmu.ac.uk](mailto:kmacdonald@qmu.ac.uk)**

**If you would like to discuss this study with someone independent of the study please contact: Dr Jan Gill, Senior Lecturer, QMU. [jgill@qmu.ac.uk](mailto:jgill@qmu.ac.uk)**

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team  
2nd Floor  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG

Tel: 0131 465 5708

Thank you for taking the time reading this information sheet.

Return slip

**Exploring interactions between young expert patients and health care professionals.**

I am interested in taking part in the study

I understand that I am under no obligation at this stage and am free to withdraw at any stage

My name is.....

My contact Details are.....

.....

.....

Please return to either Nurse Specialist at clinic

Or

Post in box at out-patient clinic

Or

Post in SAE provided to: Kath MacDonald (principal researcher)

**APPENDIX 7: Consent Form: patients    Version 2 (pt consent form ) 9/8/11**

**CONSENT FORM (patient)**

Title of Project:

**Exploring social interactions between Health Care Professionals and young “expert” patients in the self management of a long term condition**

**Name of Researcher:** Kath MacDonald

Please initial box

1. I confirm that I have read and understand the information sheet dated 9/8/11 (version 2 (pt) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that information I give will be audio taped, that tapes will be destroyed at the end of the study, and that any information collected about me will have my name and address removed so that I cannot be recognised. ☐
4. I understand that whilst direct quotations may be published in reports and journal articles, my name and any place names will be removed from the data so that I cannot be recognised from it. ☐
5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Queen Margaret University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
6. I agree to my GP being informed of my participation in the study. ☐
7. I agree to having an observer sit in on my consultation at clinic. ☐  
I agree to taking part in an interview to discuss the consultation. ☐

(You may choose to tick one or both boxes).

8. I agree that you may approach the following Health care Professionals whom I consult with to invite them to participate

Name of professional (1) \_\_\_\_\_

Job Title \_\_\_\_\_

Place of work \_\_\_\_\_

Name of professional (2) \_\_\_\_\_

Job Title \_\_\_\_\_

Place of work \_\_\_\_\_

Name of professional (3) \_\_\_\_\_

Job Title \_\_\_\_\_

Place of work \_\_\_\_\_

\_\_\_\_\_

Name of Patient

Date

Signature

\_\_\_\_\_

Name of Person  
taking consent

Date

Signature

\_\_\_\_\_

When completed, 1 for patient; 1 for researcher site file; 1 (original) to be kept in medical notes



Queen Margaret University  
EDINBURGH

## **Participant Information Sheet**

### **Exploring interactions between young expert patients and health care professionals.**

**You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.**

#### **What is the purpose of the study?**

The purpose of the study is to explore the interactions between young “expert” patients with a long term condition (CF or Diabetes) and the Health care professionals (e.g. Doctors, nurses, dieticians) they interact with in the management of their condition.

#### **Why have I been asked to take part?**

You have been asked to take part as you have nominated by a “young expert patient” as a health care professional who consults with young people diagnosed with CF or Diabetes who attend a clinic, as part of their care.

#### **Do I have to take part?**

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. .

#### **What will happen if I take part?**

A researcher will talk to you about your interactions with young people who have a long term condition (CF/Diabetes) and the way that you work with them to manage it. The researcher would also like to sit in and observe the interactions between you and a young person with CF/Diabetes during a clinic visit.

So that the researcher does not miss any important details, she would like to audio tape the interview and the clinic consultation.

#### **What are the possible benefits of taking part?**

You may/may not get a direct benefit from taking part in this study. However the results of this study may help inform future developments in care.

**What are the possible disadvantages and risks of taking part?**

It is not thought that there are many disadvantages; however, it is possible that you or your patient would not wish anyone to sit in on your private consultation. This is your right. If you would still like to talk to the researcher about your interactions with patients then we can just talk to you without being at the clinic. The interview will last between 30 -45 mins at a place convenient to you.

**What happens when the study is finished?**

At the end of the research the researcher will write a report for submission to the board of examiners and the researcher and supervisors may publish the findings in conference reports or nursing Journals. You may be contacted when the research is in the final stages to confirm that the information you gave is a fair description of your views.

**Will my taking part in the study be kept confidential?**

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Your name and any place names will be removed from the data so that you cannot be recognised from it.

**Who is organising the research and why?**

This study has been organised as part of a Doctoral degree through Queen Margaret University and has been given ethical approval by their ethics committee.

**Who has reviewed the study?**

The study proposal has been reviewed by NHS Research Ethics. A favourable ethical opinion has been obtained from South East Scotland REC. NHS management approval has also been obtained.

**If you have any further questions about the study please contact Kath MacDonald on: 0131 474 0000 (automated system- ask for Kath MacDonald) or email: [kmacdonald@qmu.ac.uk](mailto:kmacdonald@qmu.ac.uk)**

**If you would like to discuss this study with someone independent of the study please contact: Dr Jan Gill , Senior Lecturer, QMU. [jgill@qmu.ac.uk](mailto:jgill@qmu.ac.uk)**

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team  
2nd Floor  
Waverley Gate  
2-4 Waterloo Place  
Edinburgh  
EH1 3EG  
Tel: 0131 465 5708

Thank you for taking the time reading this information sheet.



Return slip

**Exploring interactions between young expert patients and health care professionals.**

I am interested in taking part in the study

I understand that I am under no obligation at this stage and am free to withdraw at any stage

My name is.....

My contact Details are.....

.....

.....

Please return to either Nurse Specialist at clinic

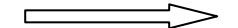
Or

Post in box at out-patient clinic

Or

Post in SAE provided to: Kath MacDonald (principal researcher)

**APPENDIX 9: GANTT CHART**  
**PROPOSED TIMETABLE OF THE PROJECT Feb 2011- June 2013**

2011-12	FEB 11	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN 12	FEB	MAR	APR	MAY	JUN	JUL	AUG	SEP	OCT	NOV	DEC	JAN 13	FEB	MAR	APR	MAY	JUN	JUL					
Planning	Proposal				ethics		Ethics approved		Recruit, consent																										
	Lit Rev						visit teams																												
Lit Review		Submit proposal																																	
		Lit review ongoing																																	
Data collection									Observation /interviews, pts, HCP's																										
Data analysis									analysis												Transcription data				Feedback to participants										
																																			
Write up		Research proposal			Ethics proposal and forms						Lit Review				Midway Report								Lit review			First draft submit									
		Lit review																																	

Dec 2012—Viva  
Dissemination/publication 2013

## APPENDIX 10: Transcript with descriptor

Charting P7 Example of coding matrix used to identify codes and categories

Description (page no in transcript)	What's this?	Initial category	Refined category	theme
<p>"well until last few years"</p> <p>"increased need for treatment since PE" (p1)</p> <p>"manage well"</p> <p>"Quite lucky, good health for someone of 26, could be a lot worse"</p> <p>"Can do same as (p2) everyone else, unless bad infection, doesn't hold me back"</p> <p>"Different if 13/14 when diagnosed, never known anything else"</p> <p>(p5)" it is partnership but no' always listened to by consultants"</p> <p>"It wasn't an infection, I</p>	<p>Health has deteriorated Precipitated by event (PE)</p> <p>Coping with burden of disease and treatment</p> <p>Sees herself as lucky for someone with cf at 26"</p> <p>Doesn't see herself as different to others, except when she has infection</p> <p>Has never known anything else but cf treatment, not new</p> <p>Doesn't always feel drs are listening to her</p>	<p>Deteriorating health</p> <p>Self- management coping strategies</p> <p>Perceptions of normality</p> <p>As above</p> <p>Routinization</p> <p>Not Being listened to</p>	<p>Impact of disease</p> <p>Constructions of coping</p> <p>Normalization/adjustment</p> <p>As above</p> <p>Embeddedness</p> <p>Barriers to partnership (attitudinal)</p>	<p>Constructions of illness</p> <p>Revisioning normality/constructions of illness</p> <p>Adjustment/constructions of illness</p> <p>Constructions of illness</p> <p>Experiences of partnership</p>

<p>know what that feels like and what's not"</p> <p>"I said its not working, they asked me what I would prefer, and make sure you're happy"</p> <p>"I know the symptoms of an infection, but with clot I couldn't say" (p6)</p> <p>"they're quite accommodating, seen within a couple of days"</p> <p>"now I'd rather deal with it than put it off, attitudes changed"</p> <p>"wee issue with the consultants, don't take too much to do with pts as they could, compared to rest of team" (p8)</p> <p>"nurses acknowledge you as a person"</p> <p>"At clinic its tick boxes medically orientated"</p>	<p>Self- knowledge (body)</p> <p>Asking for her views, getting feedback</p> <p>Self- knowledge but only when experience involved</p> <p>Team approach to self - referral accommodating</p> <p>Deals with things differently now she's older</p> <p>Consultants don't engage in non-medical aspects of her life</p> <p>Nurses engage more and know more about her</p>	<p>Experience-as attribute</p> <p>Valuing knowledge/experience Negotiating</p> <p>Experience</p> <p>Supportive team</p> <p>Growing up</p> <p>Relationship between HCP and EP</p> <p>Relationship between HCP and EP</p>	<p>attribute of expert pt</p> <p>enabler to partnership</p> <p>attribute of expert pt</p> <p>enabler to partnership</p> <p>developmental stage</p> <p>Barrier to partnership</p> <p>Relationships</p> <p>Enabler to partnership</p>	<p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Enabler/barrier to partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership/ Role of nurses</p>
--	--	---	---	---

<p>“could they think about themselves doing that (treatment), oh I ‘ve got to pick up the kids”</p> <p>“Keep coming back to nurses, more hands on, not treated like a number, see your environment”</p> <p>“they all ask the same questions, surely after 2-3 years of taking my ..... no’ too bad they could miss that out”(P9)</p> <p>“ You know the sort of info you want from clinic, pick out the bits ....and get rid of the rest”</p> <p>“I specify the things I’m bothered about, get to it quicker instead of waiting to the end”</p> <p>I wouldnae say I’ve got a chest infection and I need IV’s, I’ll put it across in a jokey way, they don’t take offence (p10)</p>	<p>Clinic follows a routine which is mostly biomedical</p> <p>HCP’s don’t understand fitting in treatment demands with all the other things they have to do</p> <p>Nurses are more involved and engaged</p> <p>Gets frustrated at being asked same q’s over at OPD. especially when nothing’s changed</p> <p>Prioritising what’s important to her and disregards other info</p> <p>She wants her issues out there at the beginning of clinic</p> <p>Doesn’t want to make a direct request, so uses different strategy to</p>	<p>Structures and processes</p> <p>Lack of empathy/holistic knowledge of pt</p> <p>Holistic knowledge</p> <p>Systems and processes</p> <p>Different agendas between HCP/EP</p> <p>Relationship with HCP</p> <p>Engagement</p> <p>? emotion work</p>	<p>Experiences of the clinic</p> <p>Organisational barrier</p> <p>Barrier to partnership attitudinal</p> <p>Enabler to partnership attitudinal</p> <p>Experiences of clinic</p> <p>Barriers to partnership</p> <p>Acceptance of experiential knowledge</p> <p>Attribute of EP</p> <p>Relationship with HCP</p>	<p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership (Nurse as broker/facilitator of good partnership?)</p> <p>Barriers/Experiences of partnership</p> <p>Ceremonial order of the clinic?</p> <p>Experiences of partnership</p> <p>Experiences of partnership</p>
---	--	---	--	--

<p>“Nurses are good at respecting me as a person because they’ve known me so long”</p> <p>“The better you get to know (staff) the better for you, you cannae say I’ve already been told that cos that’s just ignorant, so say ok and just dismiss it”(p12)</p> <p>“Definitely something about respect, you respect them but they respect me as well, my opinion”</p> <p>“Mum still coming to terms with loss of control, she’ll text, my dad is overly... you getting a cough again?”</p> <p>“ If I see them (diabetic team) its not like seeing the cf nurse or consultant, cf -it’s a friendly environment rather than a dr/pt environment”</p>	<p>address her agenda</p> <p>Nurses know her well as person not just a pt</p> <p>Duration of relationship important, new staff don’t have same understanding and will suggest things she already knows or has tried</p> <p>Respect goes both ways across the relationship</p> <p>Mum and dad still want to know whats going on with CF</p> <p>Sees the relationship with cf team as different/friendlier than with other team</p>	<p>Respect/Power/emotion work</p> <p>Holistic knowledge</p> <p>Respect Relationship with HCP</p> <p>Respect Relationship with HCP</p> <p>Parental surveillance</p> <p>Relationship with HCP’s Context?</p>	<p>Relationship with HCP</p> <p>Enabler to partnership</p> <p>Enabler to partnership</p> <p>Enabler to partnership</p> <p>Barrier/Enabler to partnership</p> <p>Enabler</p>	<p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership</p> <p>Experiences of partnership/Professional friendship</p>
---	---	--	---	---

## APPENDIX 11: Coding Index from Nvivo

### thematic framework

Name	Sources	References	Created On
attributes of the expert patient	24	295	14/12/2011 11:11
engagement	20	67	07/05/2012 16:29
articulation	7	10	18/05/2012 11:43
experience	13	31	08/05/2012 10:50
knowledge	23	122	16/05/2012 14:57
monitoring and titrating	13	34	08/05/2012 11:00
planning ahead	8	15	08/05/2012 10:46
biography	8	17	07/05/2012 15:40
constructions of illness	24	161	14/12/2011 11:25
impact of the disease	17	76	07/05/2012 15:41
priorities	19	60	07/05/2012 15:51
support	6	22	07/05/2012 16:14
experiences of partnership working	25	1115	14/12/2011 11:17
barriers to partnership working	24	283	14/12/2011 11:10
accountability	3	5	29/06/2012 16:41
agendas	5	6	29/06/2012 17:07
developmental stage	7	16	24/05/2012 12:05
emotion work	8	23	29/06/2012 16:52
lack of trust	9	19	08/05/2012 13:44
negative compliance	16	42	11/05/2012 14:40
not listening	4	8	16/05/2012 14:10
parental surveillance	8	21	29/06/2012 16:36
power	12	32	11/05/2012 15:52
relationships with hcps	12	45	09/05/2012 11:06
systems processes	12	46	11/05/2012 16:28
transition from paed	5	9	29/06/2012 16:38
enablers to partnership	24	561	14/12/2011 11:10
acceptance of experiential knowledge	17	32	08/05/2012 10:53
holistic knowledge of the patient	15	57	21/05/2012 10:29
negotiation	24	164	29/06/2012 16:37
personality	7	9	11/05/2012 16:20
positive compliance	12	26	02/02/2012 14:52
relationship with HCP	19	136	11/05/2012 16:17
respect	17	56	08/05/2012 13:54
support from & within team	17	39	10/05/2012 12:05
experiences of clinic	23	222	08/05/2012 13:58
compliance checking	14	42	02/02/2012 14:49
symptom and tx hx at opd	10	79	07/05/2012 17:05

## APPENDIX 12: Tagged data

Interview with P7 home		Labelling/tagging data
What I'm doing is I'm trying to explore I suppose what partnership means between a group of young experienced or expert patients for want of another word and we'll go back to that and the team, in your case the CF team and how you interact with them and what you have with them. A partnership? How would you define that? On whose terms does that partnership work? What are the barriers to the partnership? What helps the partnership? So that's one part of it. How do you negotiate care and treatment together – or do you? Also, I want to know a wee bit about you and how you manage your CF and that whole thing about being an experienced or an expert patient. So I suppose if we could start off, if I could ask you to tell me a wee bit about you and how you are these days and in terms of your CF, how that impacts on life in general.		
To be quite fair I did keep generally quite well up until about 2007. I developed a blood clot on my lung and since then I would say that I've deteriorated quite...not quickly but I need a lot more lvs, I used to need lvs only once every 3 or 4 years and now it's every few months and for the last year, it's been almost every month – I was hardly getting a break, up until probably the start of this year, so I've not really had a break but up until I had the pulmonary embolism I kept really well. I would say I manage my CF quite well. It holds me back to a certain extent if I'm unwell – I can't do things if I'm breathless and things but as in day to day life, it doesn't hold me back. I cope with it quite well but I think the main downfall was getting the blood clot. I don't know – I think it has damaged a bit of my lung anyway so I don't know if that has deteriorated my lungs with infections and things like that – I'm prone to it. But I try not to let it bother me so I think that generally I keep quite well – I've been to clinics and I've seen people probably younger than me who have got oxygen on so I've been quite lucky – I still class myself as quite well so I just get on with it. I could be a lot worse certainly.	001.44	3.1  3.1  3.2.1 3.2
When you see others at the clinic do you think, I'm a lot better than them – do you compare yourself?		
Ehm – I wouldn't say I compare myself – I probably think myself lucky that I am as in such good health as I am for 26. I can remember being quite young at primary school and I was kind of treated with kid-gloves. At that time, I think the age was only 16 or 18. At that time, not that I thought about it all the time but as you get older – but the average age is a lot higher than that but I mean you see these folk coming in and you can tell the folk who are round about the same age and when you see them maybe on oxygen or they are really struggling or maybe in the next room you can hear them coughing and you can hear they are a lot more breathless so I still consider myself to be relatively lucky at 26 and I wouldn't say I compare myself to them – it's just – I don't feel sorry for them – that's not the right term. It's just that I thank my lucky stars that you've not deteriorated as much – well I've got that to look forward to in the future but		3.2.1   3.2. 3.2.1







bit.....but it doesn't bother me. Ehm What else am I on?		
How long ago was that you were diagnosed?		
Well I was 18 so that would be about 8 years ago.		
Do you know, its funny because you are probably about the 7 <sup>th</sup> of 8 <sup>th</sup> patient I've interviewed and when I say, how much does the cf impact upon your life and you said, not really but when you list all the things that you have to do, the insulin, the tablets, the physio and it seems to me – and I was a CF nurse at one point as well but maybe because I've been away and I've come back to it to some extent, it just seems to me to be such a lot that you have to deal with?		
See if I was well and I was diagnosed at maybe 13 or 14, I probably wouldn't have coped with it as well because I would probably feel slightly bitter because I had been well and now I'm not but because I've been diagnosed since I was 5 months so it's all I've ever known. To me, I don't think of other people not having to take tablets – it's just like a routine – it's strange.		3.2.1
Just part of what you do?		
Yes. The biggest problem I am having just now is with my bowels believe it or not. I take Movicol every day because I've had a blocked bowel 2 or 3 times so I made a suggestion to my dr that I take it every day to try to keep things moving and he thought that if I thought it would help – and that does help but there are still times, like just now, when I'm really struggling so I had to go through and get gastrographin – that didn't work so I'm now on 2 sachets of Kleenprep every day and even that's struggling to work. It's just starting to work and that's me on my 5 <sup>th</sup> day.		3.1  1.2.5 1.2.8/1.2.1  3.1
Do you have a lot of pain in your tummy?		
Aye and I feel really bloated – like I love food but when I sit down to my dinner now – I can have a plate like this but after about a quarter of it now, I feel really really full but hopefully the Kleenprep will work but I do have problems with my bowels as well but apart from having the blood clot and a really bad infection once, I think the bowel thing is the most because you have this bloated feeling and that kind of can't be bothered way so that's probably the bigger. However, I just need to take Kleenprep and stay near a loo (laughs).		3.1
You can't go out much?		
Aye when you've got to go, you've got to go but I'd prefer that than feeling bloated. What else am I on? I'm on tablets for migraines and I'm on Omeprazole but that could be a hereditary thing because it's for heartburn and my dad's got really bad reflux and my mum's got a hiattus hernia so that could be passed down through the generations.		
So quite a lot of treatments and quite a lot of things to do but it sounds like you take it in your stride and		

it's part of your routine and it's what you've always known?		
Aye, that is it it's just that's the way it is.		3.2.1.
So that's the first bit. I want you to think now about this whole notion of your relationship with the CF team and how do you view that? Is that a partnership or what is it?		
It is a partnership – there has been times that I've felt that I've not been listened to as well as well as I should be – I wouldn't say the nurses but more the consultants. Don't get me wrong, the CF team is great and the care you get is really good and I cannot fault it. I still count myself as relatively healthy so they've obviously done something right but with the pulmonary embolus, I had that for 6 months and nobody picked up on it and I was quite....I'm not bitter about it but I felt it was left too long – I was through the hospital twice in an ambulance and a registrar told me I was just over-reacting and I was unable to breathe because I was panicking and they kept saying that it wasn't an infection and I knew it wasn't an infection because I know what that feels like and I think they tested for everything until the registrars do a kind of turnaround and I got a new registrar and he said I'm just going to send you for a CT scan just to check things and when it came back I had 2 blood clots and that's how it got....but then that wasn't the nurses, it was more getting past the registrars so sometimes that side of things, sometimes – I obviously don't know better medically and things but you know how you feel yourself and because I've had plenty of chest infections, I know what's an infection and what's not to a certain extent but apart from that one occasion, I see it as a partnership because there's times when I can give my symptoms but I basically say I know what it is, like my bowels for instance and I kind of said, 1 movicol is not working and they are happy enough to talk to me and ask what I would prefer to take and they don't just come right out and say, this is what you're getting – they do talk to you and make sure that you are happy to take what they are giving you. I must admit when it comes to things like that – I wouldn't say that I'm on any medication that I'm dead against taking. I know what's it's all for, I'm quite happy to take it – I know that it all helps – I don't think what's the point of being on that because, for instance the Tobramycin, I really couldn't take that in the nebuliser but they were happy to take me off that – they are happy to come and go with you and find something in the middle.		1.0/1.1.7 3.2.1 3.1  1.1.7 1.1.5/1.1.8 2.3  2.3 /1.2.8/2.1  1.2.8
So I suppose that's about negotiation then?		
Aye – they are good when it comes to that.	19.03 mins	
Probe, recognition of symptoms, expertise or experience, are you an expert pt?		
No really.		
Why not?		
When it comes down to a chest infection, i probably know the symptoms, but i only know myself... I couldnae say this is what a chest...., the symptoms for me are 1, my bowel starts moving really slow, I get tired and breathless, and I can see the signs and symptoms, no really just with my chest 'cos I don't get a		2.5/2.3/2.4

sore chest or anything, an infection usually starts off with a really dry cough which keeps me up at night and then my stomach starts playing up, so when it comes to that... but with any other things, for instance the blood clot, I knew it wasn't an infection, but I couldnae turn round and say right this is what...and I wouldnae say that all the time I know when I've got an infection either. Obviously the two things is cough and breathlessness and you think right, there's obviously something wrong, but I can't always tell when it's an infection, I sometimes think it's just the cold, but I usually get it checked out anyway, get yer chest sounded and things, i think maybe deep down I think I'm starting to get an infection but I like the fact that the nurses are there to check yer O2 saturation and things, there for back up, cos they're experts. You know yourself that you do start to know your own body, but there are times when I've gone through and thought that I just had a cold but I had quite a bad chest infection, so I wouldnae say I was an expert at that .		2.4  1.2.5 2.3
Have described being in tune with own body, when things are different, not as they should be?		
I know what an average chest infection looks like for myself, bowel starts to get a bit slow, cough, breathlessness, so that is a probably just a regular chest infection, so I could say I was an expert, but other aspects no' really.	0.22.26	2.3.
So experience, and being in tune, what about other aspects of expertise, knowledge technical ability?		
95% of it is down to experience. I'm nearly 27 so I've had chest infections for 26 years, and you notice wee things, no' just in your lungs, you notice other things that relate to you having a chest infection		2.3
Noticed them before? So do you build up a bank of experiences		
Yes, so if I have a cough I think it's just a cold, but then if my bowel starts playing up I think ooh that's one of the symptoms, its just experience, having the symptoms before, its not the medical or technical side, its just... and I couldnae tell if anyone else had a chest infection, its just your own body		2.3
Ok. PROBE, seeking help, put it off?		
If it starts off , I think I'll give it 2/3 days to see how it progresses, and if i can confirm that its not a head cold then i'll phone up and arrange to be seen. That's one of the things i do like about the .... they are quite accommodating, there's no hassle, they'll see you. They'll ask you a couple q's on the phone, but that's one reason i can sit on it for a couple of days cos I know if I phone up I won't have to wait another week to be seen, seen within a couple of days.		2.2  1.2.3/1.2.5
Sit on it in, because of thought of hassle ahead?		
Mmm, my attitude's changed since I had the blood clot. Before hand when I was hardly ever on IV'sli felt- oh 2 weeks of this and you've got bags and bags of stuff and cinbins, 3 x a day, isn't that often but can be a hassle, but now my attitude is I'd rather know and get it dealt with , cos I know in the back of my head, if I leave it till next week, its just putting it off for another week, and probably its gonna get worse which		3.1.2.  1.2.4

means 2 weeks of IV's becomes 3, so now my attitude is to go and get it seen get the 2 weeks iv's out of the way and get better. But i think that comes with age. Probably when i was a teenager I was like och I'm no gonna get out dancing on Saturday night, I'm no gonna be able to wear that dress, I'd just put it off, put it off, it'll maybe just go away, but now I'm older and settled, it can be a hassle , ye cannae go out partying , but because I'm settled, its no really a big deal, I take it in my stride now, but my attitude has changed from yrs ago, it would've been a hassle, I would've put it off or gone to my GP for orals, easier to take a tablet (than iv;).		3.1 1.2.4/3.1.2
Back to expert patient - is that the wrong term, should it be experienced patient?	0.27.53	
Aye.		
Or any other term?		
Aye probably experienced, don't think you can say expert patient- to me would entail a patient that knew everything, and that's no' the case, no, I wouldnae say it was.		2.3
Probe, not knowing when a new thing comes along, know something's not right but not sure what it is?		
Definitely aye, last year, infection but couldn't hear any crackles, sats 89 I thought I had a tumour or something ilwas that ill, could hardly speak, but it was an infection a deep rooted one, I would never have put it down to an infection, it did feel different, so experience is definitely a better word.		2.3
Priorities- change over time, explore social vs medical model is it acknowledged?		
Aye i think, maybe no' so much with the consultants. Wee issue, Sometimes I think they dinnae take as much to do with the patients as they could, you feel slightly just like a number, and I know ye are just a no 'cos they have thousands of pts. But the cf nurses and even the dietician, physio or the pharmacist, they always ask what you've been up to - are ye going on holiday or whatever, they always ask....about your everyday life. Obviously the centre is CF but its no all they talk about, I'm looking for a wee part time job the now and they're always asking how I'm getting on wi' things and if they can help. The nurses acknowledge that you are a person, but the higher up you go the less they are like that, there's quite a good rapport with the nurses, probably because you see them more, so i would say that there's quite good.		1.1.5 1.2.5/1.2.7  1.1.6 1.2.5
Probe further		
I suppose at clinic it is quite medically orientated, em but its not always, .....sometimes i go up to the ward to be seen, saying that they do ask you a couple of questions, but a lot of it is (medical)they're probably just making conversation as well. At clinic its more tick boxes- they do ask, but most of it is medically orientated.		1.1.8/1.3.3  1.1.8
Is that a problem?		
I don't think it is, its no a meeting, a community gathering, its a hospital so I expect them to be asking about your health and your treatments rather than what you had for your tea last night and what you		

were up to at night, cos what difference does that make to your health		
Further exploration about consideration of other side of life when doing tx.		
They understand there is an element of having to fit it in to your life- antibiotics etc, but I dunno how much they think about that. I mean could they think about themselves doing that? Oh I 've got to do iv's but I've got to pick up the kids, so do they actually think how....	35.36	1.1.11
Well do they?		
mm...Tricky question, probably they do to a certain extent. Sometimes i feel like They sympathise with patients a wee bit but then at the same time ...they know you've got to do the treatments, they've not- so do they think about the effect on them? cos they 're never gonna have to do it. I think they do sympathise, it must be hellish having to do ..... but don't know how much it can effect your life they've got the experience of patients telling them , some of them ....		1.1.7
Which?		
Keep coming back to the nurses, they're better at helping diagnose, giving tx, medication, they're more hands on, see more of the patients, deal with them more, see the environment you're in, not treated like a number, come and flush my port so see where I live, who I live with seeing the environment I live in, so they probably ... empathise maybe, but they'll never fully understand cos how could they?		1.2.5 1.2.7
Clinic aware of how much info you have to deal with- lots of people, have to sift and decide what's worth taking on board.	39.23	
Down to experience as well, when I was young i was mesmerised cos I always just had to deal with 1 consultant. And they all ask you the same q's, how are you keeping, hows the bowels are for me, just general same q's, and the dietician, what did you have to eat yesterday and for me she needs 3 sheets of paper, cos I constantly eat, laughs and i know they've got to ask that from the creon side of things, but surely after- I've been going to that clinic for 14 years, surely after 2-3 yrs, that I'm taking the right creon they should be able to think well she's taking her creon no' too bad, so they could miss out that bit. I dismiss stuff, i know that sounds bad but some things i get told at clinic- I think well I'm no skinny, I'm no underweight, so if she's saying to me try and do this or that- I think huh! Well I'll decide laughs, i think some of it, some of it goes on and on, if I took in everything , you would need to go with a pad and paper		1.1.8 1.1.11/3.1.2
So how could it be done better/ differently		
Well if the dietician takes your weight and its stable or whatever, and your vitamin levels are fine, why does she need to know exactly what you eat everyday, so that would cut out 5 mins. Or I dunno that I need to be asked about my diabetes at every clinic, I've never had bother with my insulin, the diabetic nurses say I can judge it quite , so there's no need..I think can I no' just go over this at the actual diabetic clinic, unless you've got something to ask, that's different. I think having to see everyone at every clinic can be a bit time consuming, and can sometimes be a waste of time, could they come in pairs? The info		1.1.8 1.2.7

we give the dietician and the pharmacist is exactly the same, they maybe have something slightly different to say to you but The info we give the dietician and the pharmacist is exactly the same and it is repetitive, a lot of it is waiting about ,in between seeing folk - you can be sitting yourself in a room for 20 mins thinking...i think when you come to a clinic you know the sort of information you want out of a clinic, if I'm going to a clinic today, i want to find out how i can help my stomach and that side of things and probably I would want them to sound my chest cos I've got a bit of a head cold, and probably there's nothing else bothering me so that's the 2 main things I'm going to that clinic for. So unless there's something new or they're introducing something, everything is just deid. You pick out the bits and you get rid of the rest, sometimes you can go to ¾ clinics a year and each time you go you're looking for totally different information,		1.1.11
So that implies to me that each time you go to clinic you have an agenda?		
Mm hm, aye,		
So do you declare that up front?		
Yes, now I do.		2.1
Since when?		
I'm not abrupt, i'm a lot more open now about my own opinion since i had the blood clot. Because I felt,I would rather specify the things that I'm bothered about or want to know more about the things I want fixed as such. You get to it quicker, if you wait to the end then you need to go back over it all again, in case they've missed out what you're really there for.		1.1.11/2.1
So how would that work, would you wait?		
Well the blows are first so if I'm no feeling as well I'll says my blows might not be so good today because I've got a cough, and let them know before they start. If the nurse or dietitian comes in and says something like how are you today, I'll say, as soon as I can get it in to the conversation I'll say, I'm here to ask about my stomach, I would slip it in as soon as I get the opportunity.		2.1
Do you make a demand or just give cues?		
Ehm, I would explain .. I would use "I think", ...they're quite good, if they say we're gonna put you on ...and i wisnae happy I'd say oh well I was wondering if there was anything... so for example, when I was through about my stomach and they wanted to give me kleen prep I was nae sure I could take that as its dissolved in a litre and i was really bloated and I said I dinnae think I can take thatamount of fluid, so we came to a compromise and the y gave me gastrograffin, although it never worked. So I wouldnae go in and say I've got a chest infection I need iv's , I'd say my chest feels a bit tight I think there's an infection there and then ...wait to see what their suggestion was and if I was happy with that then fine, but if I wasn't then I'd maybe try and sway it. The usual thing is they want to take me in and I detest that I hate it, so there's a couple of times when they said I needed iv's- that's fine but then admission I'd say do I really		1.2.8



need to come in, so in that sense I would try and sway it in my favour. But I would try it if they really wanted me to – like the Bramitol- I'd give them the benefit of the doubt. But i dinnae come in and say this is what I want.		
Probing further Dance of clinic, why don't patients just ask?		
See I , ....They all laugh at me, if I've got an opinion that I try to put across I will tell them but put it across in a funny sarcastic way. Rather than saying there's something in my stomach I need cleen prep they don't take it in an offensive way cos I'm jokey about it,		1.1.10
So is that you're way of getting what you want in a nice way?		
Mm hm.. sometimes. If I think that there's something that I know will help then I will suggest it in a jest , and they're usually happy to do that. I'd rather do that as do a merry dance cos sometimes you go round and round in circles, so i would say- you know you said the patient said I could've told you that 10 mins ago when the dr went out the dr, well I would say it to his face, jokingly.		1.1.10 1.1.8
Partnership is equal so if you were truly equal, why do you have to couch it in such a way?		
Cos of the kind of person I am, not because I'm scared to say to them, I dinnae always think they know better than me and I dinnae think I know better than them, sometimes you've just got to ..trial and error. Patients dinnae know everything but neither do drs, ...so if I feel that the movicols no' working, I'll say look I've had 8 movicol and its no worked, cos I know that what they're gonna suggest next so I can say I've done that I lay my cards on the table and say I've done this I've done that, and see what they come back with.	51.38	1.1.6  1.2.8/2.3
So they recognise your experience and take that on board?		
I keep going back to this 1 time when I wasn't listened to, and I knew it wasnae a chest infection, but at the same time, both times I was seen it was the weekend and it wasn't the CF team I dealt with, so the cf team aye definitely I feel they do recognise and are happy for me to have an opinion. Sometimes I think they're actually happier that you're suggesting that or wanting to try something because of you're experience, rather than them dictate to you.		1.1.7 1.1.8  1.2.8
Does that make you feel more valued?		
Aye.		
So good e.g.s of partnership, any barriers?		
Weekend staff, weekend care is horrendous (no cf team). That's one of the major barriers, there are nurse who can put grippers in but they've no got as wide a knowledge. If I took unwell on a Saturday I would hang on till Monday because sometimes I feel it's pointless if there's no a cf team there.		1.1.8
Time?		
They're accommodating, come out if they can, sometimes you have to wait a couple of days, but aye happy.		

Age?		
I think the nurses are good at respecting you as a person with a personality, because they've known me so long, they know me as a person rather than just a patient.		1.2.5/1.2.7
So is that the best thing about the partnership, their knowledge of you?		
Aye, but I feel I have a better partnership with some members of the team than others.		1.1.5
Why?		
Just personalities, nothing to do with role, just personality, same as in life there are some that I like more than others.		1.1.5
Decision making- probe –what informs discarding certain info?		
I think some stuff is almost out of a book, things they've got to say to every patient, eg, my bowels been told, well as a general you should try fibre, prune juice, but that's someone you would tell anyone, not specific cos I've tried all that and clearly you're not listening to me, that's something you'd see in a fact sheet, creon time you take it – most patients take them at start try that- well I split mine so why am I gonna change now?		1.1.7 2.3
So experience again?		
Definitely, I think if you get a new member of staff, the better you get to know someone the better for you, so they don't have the same understanding, have you tried a flutter- yes I've tried that. So you can be told something by the nurse then the dietitian and pharmacist will say the same, But you cannae say I've already been told that cost that's just ignorant, so you just say ok and then dismiss it.		2.3 2.2
So its about respect?		
Yes, but you're sitting there thinking I've just had this conversation, and that's why you can – no dismiss it but you taking it in but hearing it 4 times.		2.2 3.1.2
So summary experience counts for a lot, knowledge about self, and length of relationship important?		
I think there's definitely something there about respect, obviously you respect them but I think they respect me as well, my opinion, dinnae always think they're right and happy to acknowledge that they don't always get it right, so is a respect there as well for the patient.		
Parental involvement?		
Quite a lot, quite a close family anyway. Mum and dad take me to hospital sit in waiting room. Dinnae hide anything, help with percussion		1.1.1
Do they want to know		
Aye, my mum is still coming to terms with the loss of control she'll text me about my stomach but no overly, she'll text partner and say is she really alright is her stomach getting better? I dinnae mind that. She'll say... it's my dad who'll say you're starting to get a cough again, he's overly—and what did they say? (at clinic) they're still involved but I'm ok with that, they've done it for all those years.	1.06.50	1.1.1

That's about it thank you for your time.		
Asks about research ?		
Doesn't have same partnership at all with diabetic team.		
Turn tape back on to explore further.		
Diagnosed 9 years ago, its maybe different for people who are less controlled than me, every time they do my HbA1 C its no as if its no at a good level, never have a hypo, quite happy, only recently become (last year) confident altering my insulin. I was happy enough when I was first starting to do it, but preferred to have someone there to phone, my sugars 13 should I take 2 units before I go to bed or leave it, but I've no even got a number for the diabetic clinic.		
Never done that		
Did at beginning for ¾ months, but not sure why no longer. If I had a problem I would probably phone the CF nurse, seen 6/12 at diabetic cf clinic and stable and had no reason to phone them. But even if I ever have to its nothing like seeing a cf nurse or consultant.		
Why not?		
Well i dunno if its that they dinnae see me as much . the cf team you know them its a friendly environment rather than a dr/pt environment.		
Back to length of relationship?		
Probe if only diabetes would be different?		
Discussion so about frequency of interaction as well as length of time.		
Cf unique?		
Can't think of another illness which entails so much, diabetes is blood sugar, cf- different aspects, lungs, pancreas, liver, joints, diabetes , so maybe because there are so many things that can flail up, thats why – don;t know anybody else with that same kind of partnership, not even with my GP.		
That's the norm GP often bypassed .	08.43	

**APPENDIX 13: Thematic chart, Theme 1.0 Experiences of partnership 1.1 Barriers to Partnership: attitudinal, organisational, developmental**

**Key P** = Patient  
**HCP** = Health Care Professional  
**C** = Carer

1.1.1 Parental Dependence & surveillance	1.1.2 Lack of trust	1.1.3 Developmental stage	1.1.4 Competing agendas and compliance	1.1.5 Relationship between pt/hcp	1.1.6 Power dynamics
<p>She makes me feel safe,(mum still comes to clinic) <b>P1</b></p> <p>Still rely on my mum, come with instructions today <b>P2</b></p> <p>You havenae taken your enzymes cos the place is stinking <b>C3</b></p> <p>Mum makes up tabs daily <b>P3</b></p> <p><i>Parent interjects at OPD about son's skin</i> <b>P3</b></p> <p>Relative very involved in</p>	<p>Covert administration of meds, should've told them ages ago but thought they might take them off me <b>P9 (Xref emotional labour)</b></p> <p>In the past I would've looked at the tests but now would err on side of listening to what they say and treat. I do wonder if any of us are getting the truth about how much drug is taken, it's true we don't trust them, should we trust them? No <b>HPC2</b></p> <p>Medical staff will</p>	<p>In paed's it wasnae between me &amp; drs it was between you (<i>parent &amp; Dr</i>) Dinnae get moaned at so much (at adult clinic).<b>P3</b></p> <p>Think they're bullet proof at this stage, easier at paed's we knew where to turn <b>P3 Parent (Xref parental surveillance)</b></p> <p>Just grew up.I think having the baby, it was a gradual thing.</p>	<p>The CF team are always gonna be,,, they want you to do physio twice a day 3 x a day. They've got high expectations and sometimes you wonder, do they actually think I've got a social life, I've got a job, I've got a family and I've got a house and I've got all these other things happening <b>P1</b>,</p> <p>Issue of putting things off in the hope that it'll get better, but rarely does, <b>P1,3,5,6,9</b></p>	<p>Pt trusts nurses more than anyone, would just like to deal with them, <b>P1, 4, 5, 6</b>,</p> <p>Sometimes it feels like they just want you to focus on your CF, and that's all they see, Others never take into account life anything but CF <b>P1</b></p> <p>Knowing that I played football 2 x wk, sort of tells them there's nothing wrong with me but it's not on the form! <b>P2</b></p> <p>Nurses treat you like a person, easier to talk to <b>P1, 4,6, 7,8, 9</b></p>	<p>When you're in the ward they've got all the power, you have power at home <b>P1</b></p> <p>Not scared to say to them, they're no better than me nor I them <b>P7</b></p> <p>Drs are high up, nurses in the middle dietitian and physio lower, feel more equal with physio and dietitian <b>P9</b></p> <p>Some people don't want power, why are you asking me that, that's your job! <b>HPC3</b></p> <p>At ward round you're on a different level to Dr's in the pts eyes</p>

<p>supporting her <b>P6</b></p> <p>Mum &amp; dad take me to hospital, help with percussion, mum still coming to terms with loss of control <b>P7</b></p> <p>No' hands on but I phone her or text every day, and I go on facebook and see whats she's doing. Never used to go on facebook, but other people were saying to me oh see she's doing this or that and I felt a bit shoved oot. I actually felt that way when she first came up here. So strange that they werenae asking me the questions, everything directed at her, took me a few months to get.. i felt worthless. Still comes home when unwell "come &amp; get</p>	<p>argue that you get 3 different answers to a question so need to keep checking <b>HCP 3,4, 11</b></p> <p>They are a very honest bunch and I dunno why that is. <b>HCP6</b></p> <p>Times I haven't listened properly and you've got to acknowledge that <b>HPC7</b></p> <p>Sometimes I feel I'm just going along and you know they're not doing things <b>HCP 6, 8</b></p> <p>Few pts who refuse to obs and GTT, they get away with things more than in other areas <b>HCP 8</b></p> <p>Pt who is aware of symptoms sometimes says this just isn't working, so sometimes the team will listen and</p>	<p>Back then was stupid, not bothered, wanted to have a good time. Aye I do my physio (not) <b>P5</b></p> <p>Attitude now is get things sorted, less likely when younger, priority was dancing on a sat. night. Think as youy grow up you mature, don't need to experience things twice <b>P7</b></p> <p>Can't continue doing this to myself, had an epiphany <b>P9</b></p> <p>Less of a partnership than I would like particularly in transition, adolescent pts; no eye contact, won't speak Most common problem</p>	<p>Would tell them I didn't do anything, no point hiding it <b>P1, 4, 5,9</b></p> <p>I don't want to do it, I've been doing it for years, its boring <b>P3</b></p> <p>Wouldn't have done it in past (<i>nebulizer</i>) but now I'd gie it a bash <b>P4 (X ref dev stage)</b></p> <p>Could probably avoid blockage if I got the finger out and start taking stuff when the symptoms start <b>P5</b></p> <p>Some days can't fit anything in, but do my best <b>P6</b></p> <p>Don't like physio, I'm lazy, would rather play the X box <b>P9</b></p> <p>Pts have good reason</p>	<p>Well it's not a community gathering, I expect them to ask medical questions <b>P7</b></p> <p>Rest of team rely on nurse to fill in gaps (holistic knowledge) and flag issues <b>HCP 1,2,3,7, 10, 11</b></p> <p>Sometimes you feel like a naughty schoolboy <b>P1</b></p> <p><b>Most pts acknowledge there is negotiation (apart from P1, see enablers)</b></p> <p>I don't challenge what they say I trust them to make the decisions <b>P6 (Xref trust) (unique in group)</b></p> <p>Wee issue with consultants, don't take as much to do with you as they could <b>P7</b></p>	<p><b>HCP5</b></p> <p>Rarely do Dr's disagree with you, they're the middle man, Dr is queen bee, they're the worker bees, influence decisions, make them and get them to agree. <b>HCP 4,5,6</b></p> <p><b>Nurses are most powerful team members according to Drs –</b></p> <p>Nurses are most skilled, will feed appropriate lines <b>HCP1</b></p> <p>You have the power of more knowledge <b>HPC 8</b></p> <p>Patient with late diagnosis say you decide <b>HCP 10</b></p> <p>Power can shift according to context</p>
--	--	--	---	---	--

<p>me” OPD “what did I tell you you’ve lost weight” <b>C8</b></p> <p>Mum wants to know what’s going on, I just won’t tell her <b>P9</b></p> <p>Young group, have to talk to parents Starting from a point where parents had all the power &amp; control <b>HCP 1</b></p> <p>Pt in mid 20’s won’t let them make changes cos his mum will quiz him and belittle decisions <b>HCP3</b></p> <p>Pts coming to clinic for 10 yrs still have huge parental involvement <b>HPC 10</b></p>	<p>sometimes they won’t. Pts have an incredible knowledge and look things up, chat to others, that’s generally respected but when there is a medical reason for not following up there’s sometimes a bit of a clash <b>HPC10</b></p> <p>Studies on adherence suggest 30 % so when patients say 50% we assume 30. I err on the side of optimism, but been burned before <b>HCP11 (Xref non compliance)</b></p>	<p>is explicit or covert non adherence <b>HCP2 (x ref compliance)</b></p> <p>Do lots of joint visits at transition clinic, seems to work better <b>HCP 3</b></p> <p>Job is to educate and refresh, on regular basis, particularly with younger transition pts.<b>HCP5</b></p> <p>Disabler to partnership; dealing with teenagers, its like rebelling or a big challenge <b>HCP11</b></p>	<p>not to go along with tx. Reasons worried about side effects, no time, don’t see benefit. Don’t think they’re devious about it, some will conceal the truth &amp; are inconsistent in reporting <b>HCP1</b></p> <p>Physio says you’ve not been taking your nebs for 6/12 so we’ll stop it and consider it in the future <b>HCP3</b></p> <p>A lot of what we’re dealing with is around compliance <b>HCP4</b></p> <p>Got a list of people that I work with regarding adherence but not keen to have a naughty clinic <b>HCP 11</b></p>	<p>They’re all the same to me its about respect, my mum would kill me <b>P8</b></p> <p>Certain people I’ll speak to others I won’t, 1 of the dr’s gives of himself, if you give me something I’ll give you something <b>P9</b></p> <p>Its personalities some people get on better than others <b>P7, HCP1</b></p> <p>HCP’s should cover holistic aspects, reliant on CNS, better than we used to be <b>HCP1</b></p> <p>Not possible for medics to have same holistic understanding as nurses. <b>HCP2</b></p> <p>CNS ‘s have breadth and depth of knowledge second to none, they are the cornerstone <b>HCP7</b></p>	<p>between pt and HCP <b>HPC3, 8,10,11</b></p> <p>Pts can be quite intimidating especially with new staff <b>(HCP1,2,3,4,5 7, 8, 10, 11)</b></p> <p>Like to think power is shared in ideal concordant relationship <b>HCP2</b></p> <p>Think more than any other group we allow the autonomy <b>HCP11</b></p> <p><b>Almost universally HCP’s think they are too soft and pts get away with much more, they will never be discharged, some pts agree that this is the case (Xref negotiation)</b></p>
---	---	--	---	--	---

				Almost all HCP's refer to uniqueness of relationship; down to its duration, frequency of contact, small nos, nature of illness	
--	--	--	--	--	--

1.1.7 Systems and processes	1.1.8 not listening	1.1.9 accountability	1.1.10 Agendas	1.1.11 Emotion work	Comments
<p>They expect you to drop everything &amp; come to the ward, its not easy with work. <b>P1</b></p> <p>I guess its, (sighs) ..clinic appts happen what 6/8 times a year, and you're there for 21/2 hrs, you're stuck in a room, been questioned, every body asks the same questions, goes over the same things and</p>	<p>And the Dr said you're not listening to me, trust me on this and I thought he's not listening to me, and it didn't work <b>P1</b></p> <p>Dr said no you're not listening to me, trust me on this &amp; I thought he's not listening to me and it didn't work <b>P2</b></p> <p>There's been times when I've not been</p>	<p>Obviously medical questions, that's our job <b>HCP2</b></p> <p>Obviously the buck stops with us and if something goes wrong we have to answer why <b>HCP3</b></p> <p>Only by asking questions do you find out there's something's wrong <b>HCP8</b></p> <p>If you don't ask you don't know. We still</p>	<p>I want to get it out of the way as quickly as possible. If there's a problem, fix it and leave <b>P1</b></p> <p>Rest of the team don't take an interest in the non-medical side <b>P6</b></p> <p>Less concerned with social life now I'm settled, and more likely to prioritise CF. If I'm going in today I want a solution for my</p>	<p>I'm always anticipating when the next infection will be, over analyse; causes a lot of anxiety <b>P1</b></p> <p>Could have told him that 10 minutes ago but new Drs have to have their place (X ref 1.1.5 )<b>P4</b></p> <p>You put it in a jokey way so as not to offend (request at clinic) <b>P7</b></p>	<p><i>Italics are authors interpretations and additions to context.</i></p> <p><b>Bold comments within table are summations of multiple(similar) comments</b></p>

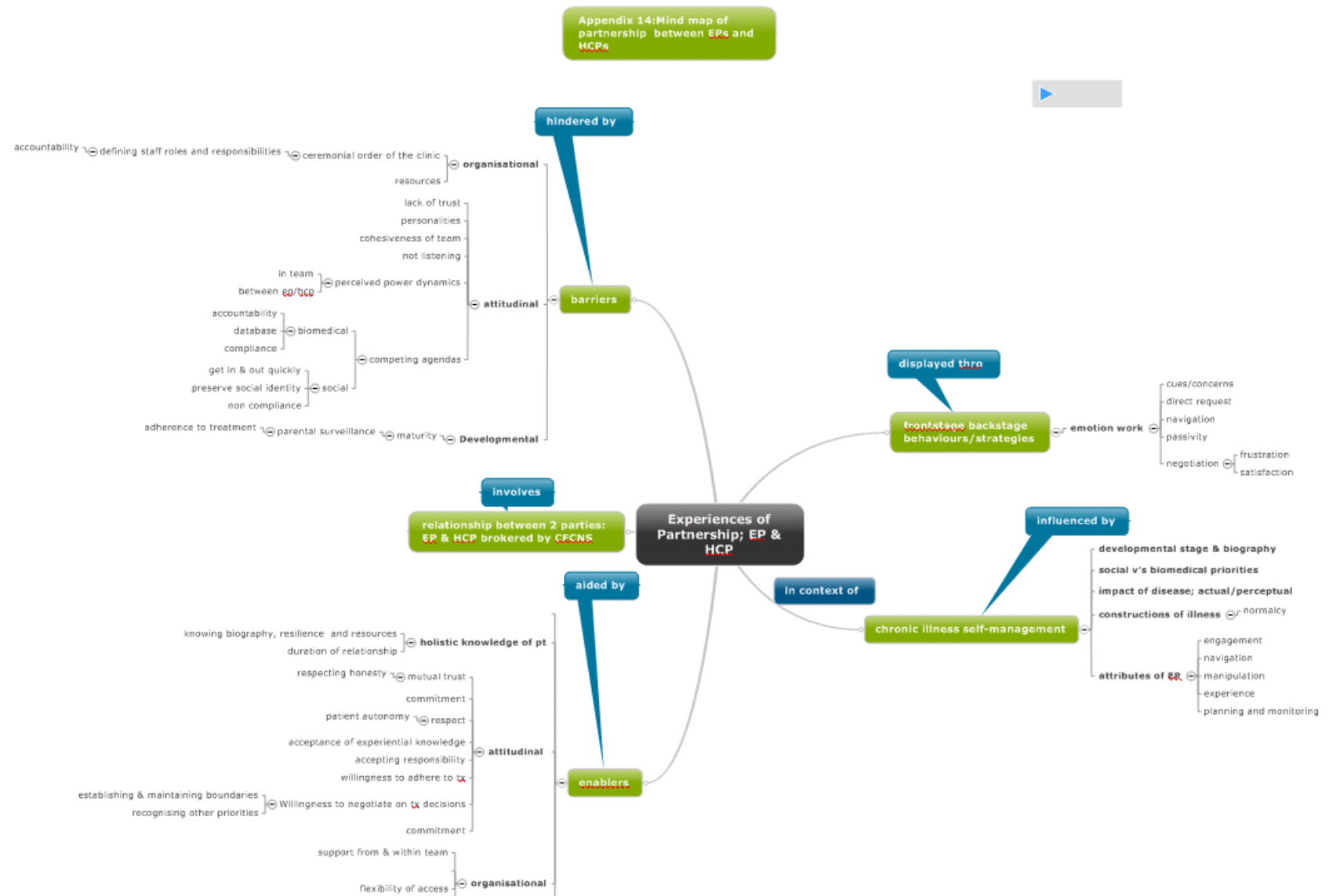
<p>you just feel like you're repeating yourself a lot <b>P1</b></p> <p>Basically they're just filling out forms, they don't necessarily fit everyone <b>P2</b></p> <p>you only see the Drs a few times then they change, it's a pain <b>P4</b></p> <p>Repetition, I'm the same guy as last time, so don't bother coming, nothing new (OPD) <b>P5</b></p> <p>Clinic is tick boxes; medically orientated, been going for 14yrs, surely when they see (stability) they could miss that out. <b>P7</b></p> <p>Clinic is time consuming and repetitive, communication doesn't get passed on (scan results) <b>P8</b></p>	<p>listened to as well as I should be, I knew it wasn't an infection <b>P7</b></p> <p>In the past would look at objective results but now would err on side of listening to what the patient says and treat <b>HCP2</b></p> <p>There have been times I haven't listened properly and you've got to acknowledge that <b>HCP7</b></p> <p>There is a patient who is incredibly knowledgeable, sometimes says this isn't working and sometimes the team will listen and sometimes they won't, and now she's ended up on the drug she wanted in the first place, but more</p>	<p>have to look after them medically, are you missing something? Have to have your radar up even with knowledgeable patients <b>HCP9</b></p>	<p>stomach and sound my chest cos I've got a head cold <b>P7</b></p> <p>You pick out the bits and you get rid of the rest, sometimes you can go to ¾ clinics a year and each time you go you're looking for totally different information. <b>P7</b> (Would rather specify issues of concern up front than go through "dance of clinic" <b>X-Ref 1.1.7</b>).</p> <p>Not CF but having a life (priority) <b>P9</b></p> <p>Yes the team is sufficiently experienced to know patients won't do everything- except the new Drs.(<b>X ref non compliance 1.1.4</b>)</p> <p>I think the no. of</p>	<p>They fish for antibiotics; not sure they're gonna get them <b>P8</b></p> <p>(Covert use of drug for pain relief) Didn't know if they would take them off me (so didn't tell them) <b>P9</b></p> <p>When people are in the terminal phase, its harder on the HCPs; talking to parents, partners or children</p> <p>If patients want antibiotics before going on hols they will give us an excuse to give them rather than saying "I'm going on holiday" <b>HCP1</b></p> <p>Emotional part of the consult tends to get picked up by others (CNS/physio) <b>HCP6</b></p> <p>I ask for support if</p>	
---	--	--	--	--	--



<p>Systems and processes; team must be quite clear on patients they wouldn't refer for transplant. I know CNS's channel patients, its sometimes overt and that's how a team should work <b>HPC1</b></p> <p>There's still a hierarchy in the team <b>(X ref to power 1.1.6) HPC3</b></p> <p>Ward round; dr comes in blah blah, pt won't speak but will catch nurse after <b>(X ref 1.1.6) HPC4/5</b></p> <p>Clinic is not patient led, patients may not speak there, they'd speak to the nurse afterwards <b>HPC6</b></p> <p>Occasionally miffed when Drs write in the</p>	<p>ill <b>HCP9</b></p>		<p>instances where it's essential that the pt comes on board today are very few, so.... (<i>gentle persuasion</i>) <b>HCP1</b></p> <p>You've got to pick your battles, (<i>treatments very rarely urgent, play long game</i>) <b>HCP2</b></p> <p>As a Dr you end up covering more than 1 issue at a time so it's tricky <b>HCP3</b></p> <p>Dr's are very prescriptive; how's your chest, others pragmatic, spend time talking about stuff outside CF. <b>HCP6</b></p>	<p>I'm struggling with a patient; if I'm getting out of my depth and I need more input, most emotional job ever <b>HCP9</b></p> <p><b>Seems like nurses do most of emotion work and this is expected and condoned</b></p>	
---	------------------------	--	---	---	--

physio part of the clinic form, and it may be inaccurate. <b>HCP9</b>					
--	--	--	--	--	--

APPENDIX 14: Mind map – Partnership between EP's and HCPs (Figure 2)



## APPENDIX 15: Ethics application (draft)

Full Set of Project Data

IRAS Version 3.1

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters)  
Negotiating healthcare through partnership

1. Is your project research?

☒ Yes ☐ No

2. Select one category from the list below:

- ☐ Clinical trial of an investigational medicinal product
- ☐ Clinical investigation or other study of a medical device
- ☐ Combined trial of an investigational medicinal product and an investigational medical device
- ☐ Other clinical trial or clinical investigation
- ☐ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- ☒ Study involving qualitative methods only
- ☐ Study limited to working with human tissue samples, other human biological samples and/or data (*specific project only*)
- ☐ Research tissue bank
- ☐ Research database

If your work does not fit any of these categories, select the option below:

☐ Other study

2a. Please answer the following question(s):

- a) Does the study involve the use of any ionising radiation? ☐ Yes ☒ No
- b) Will you be taking new human tissue samples (or other human biological samples)? ☐ Yes ☒ No
- c) Will you be using existing human tissue samples (or other human biological samples)? ☐ Yes ☒ No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

- ☐ England
- ☒ Scotland
- ☐ Wales
- ☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- ☐ England
- ☒ Scotland

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

<input type="radio"/> Wales <input type="radio"/> Northern Ireland <input type="radio"/> This study does not involve the NHS
<b>4. Which review bodies are you applying to?</b> <input checked="" type="checkbox"/> NHS/HSC Research and Development offices <input checked="" type="checkbox"/> Research Ethics Committee <input type="checkbox"/> National Information Governance Board for Health and Social Care (NIGB) <input type="checkbox"/> Ministry of Justice (MoJ) <input type="checkbox"/> National Offender Management Service (NOMS) (Prisons & Probation)
<b>5. Will any research sites in this study be NHS organisations?</b> <input checked="" type="radio"/> Yes <input type="radio"/> No
<b>6. Do you plan to include any participants who are children?</b> <input type="radio"/> Yes <input checked="" type="radio"/> No
<b>7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?</b> <input type="radio"/> Yes <input checked="" type="radio"/> No  <i>Answer Yes if you plan to recruit participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the NIGB Ethics and Confidentiality Committee to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.</i>
<b>8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?</b> <input type="radio"/> Yes <input checked="" type="radio"/> No
<b>9. Is the study, or any part of the study, being undertaken as an educational project?</b> <input checked="" type="radio"/> Yes <input type="radio"/> No
<b>9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?</b> <input checked="" type="radio"/> Yes <input type="radio"/> No
<b>10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?</b> <input type="radio"/> Yes <input checked="" type="radio"/> No

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### Integrated Research Application System Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

**Short title and version number:** (maximum 70 characters - this will be inserted as header on all forms)  
Negotiating healthcare through partnership

#### PART A: Core study information

##### 1. ADMINISTRATIVE DETAILS

###### A1. Full title of the research:

Negotiating healthcare through partnership: Exploring social interactions between Health Care Professionals and young "expert" patients in the self management of a long term condition (CF/Type 1 diabetes).

###### A2-1. Educational projects

Name and contact details of student(s):

###### Student 1

	Title Forename/Initials Surname
	Mrs Kath MacDonald
Address	School of Health Sciences
	Division of Nursing, OT & AT
	Queen Margaret University Edinburgh
Post Code	EH21 6UU
E-mail	kmacdonald@qmu.ac.uk
Telephone	01314740000
Fax	01314740001

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:

Professional Doctorate in Health and Social Science

Name of educational establishment:

Queen Margaret University

Name and contact details of academic supervisor(s):

###### Academic supervisor 1

	Title Forename/Initials Surname
	Dr Shona Cameron

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

Address	School of Health Sciences Division of Nursing, OT & AT Queen Margaret University Edinburgh
Post Code	EH21 6UU
E-mail	scameron@qmu.ac.uk
Telephone	01314740000
Fax	01314740001
<b>Academic supervisor 2</b>	
	Title Forename/Initials Surname Dr Margaret Smith
Address	School of Health Sciences Division of Nursing, OT & AT Queen Margaret University Edinburgh
Post Code	EH21 6UU
E-mail	msmith@qmu.ac.uk
Telephone	01314740000
Fax	01314740001
<b>Academic supervisor 3</b>	
	Title Forename/Initials Surname Dr Lindesay Irvine
Address	School of Health Sciences Division of Nursing, OT & AT Queen Margaret University Edinburgh
Post Code	EH21 6UU
E-mail	lirvine@qmu.ac.uk
Telephone	01314740000
Fax	01314740001

Please state which academic supervisor(s) has responsibility for which student(s):  
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)
Student 1 Mrs Kath MacDonald	<input type="checkbox"/> Dr Shona Cameron <input type="checkbox"/> Dr Margaret Smith <input type="checkbox"/> Dr Lindesay Irvine

A copy of a current CV for the student(s) and the academic supervisor(s) (maximum 2 pages of A4) must be submitted with the application.

**A2-2. Who will act as Chief Investigator for this study?**

☒ Student  
☐ Academic supervisor  
☐ Other

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### A3-1. Chief Investigator:

	Title Forename/Initials Surname
	Mrs Kath MacDonald
Post	Lecturer in Nursing
Qualifications	RGN, MSc, PC Cert Ed.
Employer	Queen Margaret University
Work Address	School of Health Sciences
	Division of Nursing, OT & AT
Post Code	EH21 8UU
Work E-mail	kmacdonald@qmu.ac.uk
* Personal E-mail	kmacdonald@qmu.ac.uk
Work Telephone	01314740000
* Personal Telephone/Mobile	07988958549
Fax	01314740001

*\* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.  
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.*

### A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project? This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Dr Kathy Munro
Address	Head of Division
	Nursing, OT & AT
	Queen Margaret University Edinburgh
Post Code	EH218UU
E-mail	
Telephone	01314740000
Fax	01314740001

### A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available):	11/SS/0001 (rec ref)
Sponsor's/protocol number:	RTT153481 (Policy no )
Protocol Version:	
Protocol Date:	
Funder's reference number:	
International Standard Randomised Controlled Trial Number (ISRCTN):	
ClinicalTrials.gov Identifier (NCT number):	
European Clinical Trials Database (EudraCT) number:	
Project website:	

Ref.Number Description	Reference Number
------------------------	------------------



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

**A5-2. Is this application linked to a previous study or another current application?**

☐ Yes ☒ No

Please give brief details and reference numbers.

### 2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

**A6-1. Summary of the study.** Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. This summary will be published on the website of the National Research Ethics Service following the ethical review.

Scotland now has approximately 40% of its population living with a long term condition (LTC). Many of these people are self managing their conditions. This is in keeping with the Government's drive to increase patients' engagement in involvement and responsibility for their health. The desire for this partnership and participatory approach is well documented in the nursing and medical literature as are the barriers to its implementation.

In recognition of patients' contribution to self management the term "expert patient" has evolved. LTCs are traditionally associated with middle age or elderly populations, however young people also have LTCs and self manage these and may also be viewed as experts. Little is yet known on how this expertise is viewed and used during consultations between young people with a LTC and the Health Care Professionals (HCPs) with whom they interact.

The purpose of the research is to explore the strategies used by young "expert patients" (aged 18-35) with Cystic fibrosis or Type 1 diabetes and healthcare professionals to negotiate and maintain partnership?

1. How do young "expert patients" and the healthcare professionals with whom they engage perceive partnership?

2. What are the perceived outcomes of partnership from the patients' and health care professionals' perspectives?

3. What are the perceived and observed factors that enable or inhibit partnership?

4. How do young "expert patients" report their use of past experiences of

Interactions with health care professionals to negotiate care management strategies in future encounters?

A descriptive qualitative case study approach using non participant observation and semi structured interviews of up to 10 patients and 10 HCPs will be adopted.

The data collection will take place in out-patient clinics in a Hospital in Edinburgh between Oct 2011- Jun 2012.

**A6-2. Summary of main issues.** Please summarise the main ethical and design issues arising from the study and say how you have addressed them.

Definition of terms:

Partnership: A concept involving relationship, shared decision making, power-sharing, patient autonomy, shared knowledge, participation, communication and professional competence. (Hook 2006).

"Expert Patient": "people who have the confidence, skills information and knowledge to play a central role in the management of life with chronic disease" DoH (2001)

Self management: the process each person develops to manage their conditions (LTCAS 2008).

Long term conditions: (also called chronic conditions) are conditions that last a year or longer, impact on a person's life, and may require ongoing care and support. The definition does not relate to any one condition, care group or age category, so it covers children as well as older people and mental as well as physical health issues. (SG 2009)

Background

The concept of partnership between patients and Health Care Professionals (HCPs) is not new and is linked to the ethics of healthcare and the recognition that patients have rights and responsibilities to be involved in health care management and decisions (WHO 1978).

Changing demographics and an increase in LTCs have seen a strengthening of the focus on partnership approaches (particularly with regard to self management of LTCs) as evidenced by the language in policy documents emphasising empowerment of patients and "a mutual NHS" (DoH 2006, SE 2007, LTCAS 2008, LTCC 2010, DH 2010, SG 2010) and the increasing number of citations with regard to partnership in the health and social science literature (Hook 2006).

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

In recognition of patients' contribution to self management the term "expert patient" has evolved (DoH 2001). There is much debate in the literature at the amorphous use of the term "expert patient" and the definition of expert. Expertise is not a concept easily applied to both HCPs and patients and it would appear that the use of the term "expert patient" has invoked anxiety and discomfort among health care professionals who may feel threatened by its usage, (Shaw and Baker 2004, Daiski 2004, Corlett and Twycross 2006, Wilson 2007). It is contended that these reactions may have an impact on partnership between the two groups.

LTCs are often associated with midlife and old age. The author comes from a background of working with young people with a LTC (cystic fibrosis) and it is clear that expertise is also present in this group. Many are diagnosed at a young age and may have built up a repertoire of skills and knowledge which informs their self management. There is little known in the literature about the young expert patient appears and this issue was thought to merit further exploration.

The PI has a background as a nurse specialist working with young people with Cystic Fibrosis (CF). This proposal links to her previous research which unearthed the concepts of the patient as expert and barriers to achieving partnership working. Thus this area was felt to warrant further exploration; particularly in light of the policy initiatives of patient inclusion and involvement in health care, the increased number of citations regarding partnership in the health and social science literature in recent years and the debate around the term "expert patient".

The study has been submitted to Queen Margaret University as a doctoral proposal and has been subject to review, feedback and support from the Director of studies, supervisors and head of doctoral research at the institution. The proposed study seeks to explore the nature of partnership between young "expert patients" who self manage a LTC and the HCPs with whom they interact.

### Methods

A descriptive qualitative case study design is proposed.

The case study is the group of expert patients located from two patient groups, (CF and Type 1 diabetes, from a large teaching hospital in Edinburgh) and the health professionals they encounter in their partnerships. These groups were selected as they have sufficient numbers of young people who have lived with a long term condition for a significant period of time (see inclusion criteria).

Non participant unstructured observation and semi structured interviews are the proposed methods for the study.

Observation will take place in consultation settings (Out-Patients) between health professionals (e.g. nurses doctors, dieticians) and young (aged 16-35) "expert" patients with either CF or Type 1 diabetes. Semi structured interviews will be the method used to discuss the experiences of partnership working. Interviews will be conducted after the observed consultations and will discuss the experiences of partnership working and deconstruct the consultation event. HCPs and young expert patients will be interviewed separately and data will be audio taped and transcribed verbatim. It is expected that interviews with HCPs will be undertaken in their workplace. Interviews with patients may take place in the out-patient setting but could also be undertaken in their home, if that is their preference.

Recruitment: A purposive sample of up to 10 self selecting "expert patients" (as defined by the literature-Tyremen 2005) and up to 10 health professionals who they encounter in their clinic consultations will be sampled.

### Inclusion criteria

- Patients aged 16-35 years, of either gender, who speak English, with CF or Type 1 diabetes who attend clinics in Edinburgh.
- Patients should have transitioned from either paediatrics or another adult clinic over a year ago as it will be important that they have built up a relationship with the HCPs whom they encounter.
- Diagnosis of CF/IDDM which requires a significant amount of self management, (Some CF patients may also have diabetes- this would not exclude them as long as they have been managing one LTC for >5 yrs).
- Must have lived with the disease for 5 years or more (Suggests a level of experience of living with a LTC)
- Must attend a specialist clinic in Edinburgh area (Logistics of travel and access for researcher)
- Views themselves or are viewed as "expert" patients- have to self manage a range of treatments (medicines/insulin/physiotherapy/diet) and use skills such as self monitoring, testing and adapting treatments using experiential knowledge. (Tyremen 2005). Patients may self select, and deselect as appropriate.
- Must attend at least 2 Consultations with diabetic/CF team per annum and have attended a consultation within 6 months, (suggests engagement with HCPs on a relatively regular basis).
- HCPs (nurses, doctors, physiotherapists, dietiticians, psychologists, pharmacists) should be working with patients with CF or Type 1 diabetes in consultation settings.

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### Exclusion Criteria

- Patients who have been self managing for less than 5 years.
- patients out with the 16-35 age range.
- Patients who have transitioned from a paediatric clinic or another specialist centre within the past year.
- Patients who have not consulted with a HCP at least 6 monthly.
- Patients who do not understand or speak English.
- HCPs who do not consult with patients with CF or Type 1 Diabetes

A two stage recruitment strategy is proposed:

Stage 1: Posters will be displayed in patient waiting areas in specialist out-patient clinics and adverts placed in newsletters, (e.g. Diabetes UK, LTCAS, Butterfly Trust). If potential participants are interested in receiving further information on the proposed study they should contact the researcher via the contact details on the posters and information sheets. At this stage personal or e-mail addresses will be required in order that information can be sent to participants by the researcher. The researcher will then issue information packs (containing an information sheet, consent form and stamped addressed envelope; appendices 1-4). On receipt of packs participants will be given one week to decide whether to opt into the study and post back forms, or e-mail or telephone the researcher. Reminder letters can then be sent out to those participants who have not made contact after one week.

Additionally Specialist Nurses will be made aware of the study and may also issue packs if patients express an interest to them. Information leaflets about the proposed research will be also be available at the out-patient clinics and the researcher will be in attendance at some of these clinics in order to answer any potential questions.

Stage 2: On agreement to participate, patients will then be asked to identify the health professionals they encounter in their regular consultations as part of the management of their LTC. These professionals will then be approached (by letter or e mail- Appendix 2) and invited to participate in the study. Professionals will not be given the identity of the patient who identified them as one of the health care professionals whom they consult with. Their written consent will be sought on agreement of participation (Appendix 4).

The perceived main ethical issues are:

1. Familiarity with staff in the CF unit which may create bias or make staff feel uncomfortable.
2. Raising of sensitive issues which patients may feel will threaten the therapeutic relationship.
3. Loss of confidentiality- between patients and HCPs if data is shared between them- and in general through presentation of results and inappropriate storage of data.
4. Issues of gaining informed consent of patients.
5. Observation of poor practice by the researcher during a consultation.

Issues and proposed measures to address them

1. The researcher worked in the CF unit some years ago and some of the staff (and possibly one or two of the patients) are known to her. Familiarity with staff may influence normal activity; for example HCPs may feel uncomfortable being observed by a former colleague and may behave differently.

The researcher will meet with staff to discuss the proposed study (pending ethical approval) and will spend some time in the out-patients department with the team during the recruitment phase which may help to break down any perceived barriers. The team are used to having observers, "sit in" in clinic consultations as part of their educative roles in a large teaching hospital. The role of the researcher is not to be judgemental but to observe and record the observed event. However the researcher has an awareness of subjectivity in research and this will be noted and declared throughout the research process using reflection and field notes.

2. Service users who are critical of the service may be hesitant in expressing these views for fear of offending individual HCPs and subsequently altering the relationship or the care that exists between them. This may occur through a perceived potential loss of confidentiality.

It will be stressed that participation in this study will be entirely voluntary and participants have the right to refuse to take part or withdraw from the study at any time without having to give a reason. All participants have the right to opt in or out of the observed sessions (for example they may wish to opt out if they want to discuss issues of a sensitive nature without being observed). Further, participants- during interview- have the right to choose not to discuss something which the researcher raises that has been observed during the consultation.

A contact person (Senior Lecturer at QMU) not associated with the research has been identified should participants



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

wish to raise any issues associated with the research process. This person will be named on the information sheet but the researcher will raise this again at each interview to ensure participants are fully informed of the support available. Additionally participants have access to NHS complaints procedure and this is detailed on the information sheet (Appendices 1,2).

3. To ensure confidentiality, Identifiers will be coded (voice, context, role, personal perspective) so that data presented in the final report are anonymous to readers and other participants. The small numbers in the study make it likely that HCP's and patients may recognise who has said what when questioned at interview (after the observed event) but names and Identities will not be divulged between individuals and data will be presented in such a way that patients and the health professionals they consult with are not linked (i.e. coded).

The Principle Investigator will assume responsibility for security of data collected. Coded data will be entered into a computer base. All interviews will be recorded on tape. Tapes will be transcribed verbatim. Tapes and coded data will be stored in a locked cabinet. Files stored on computer are password protected. The only other people who will have access to transcripts will be doctoral supervisors who will be unaware of identities. All raw data will be stored in accordance with QMU Retention Policy which is informed by the Data Protection Act (1998). Raw data will be stored for 5 years on completion of the research, initially on campus and then in remote secure storage. Signed consent forms will be stored separately from the data for 12 months on campus, thereafter remotely in secure storage for the duration of the retention of the raw data. The results of this project will be disseminated at various conferences and meetings and in peer reviewed journals. Direct quotations will be used in reports and publications and presented in a way to secure participant anonymity (using codes and pseudonyms).

4. Participants will be asked to provide their written informed consent prior to the consultation event and interview. Participants may choose to take part in only the interview or the observation event (as opposed to both), and that is their right. Participation is voluntary and participants have the right to refuse to take part or withdraw from the study at any time without having to give a reason. Withdrawal will not impact on their future management.

5. Theoretically, observation may raise issues of poor practice; however the researcher is aware that the health professionals under observation are experienced practitioners who hold fairly senior positions (e.g. Registrars, Nurse Specialists). However should this issue arise the researcher would address this with her research supervisors in the first instance and thereafter through the appropriate channels. If at interview patients were to report poor practice regarding HCPs, they would be advised by the researcher to report this through the normal NHS Complaints Procedure.

The researcher will adhere to the QMU's Code of Research Practice. QMU adheres to the UK Research Integrity Office Procedure for the Investigation of Misconduct in Research.

### References

- Corlett J. Twycross A. 2006(a), Negotiation of parental roles within family-centred care; a review of the literature *Journal of Clinical Nursing* 15, 1308-1316
- Daiski I. 2004 Changing nurse dis-empowering relationship patterns. *Journal of Advanced Nursing*, 48 (1), 43-50.
- Data Protection Act 1998 London, HMSO
- Department of Health (DH) 2010 Equity and Excellence: Liberating the NHS London, HMSO.
- Department of Health (DoH) 2006 Our Health Our care: a new direction for community services DoH, London
- Department of Health(DoH) 2001 The Expert Patient- a new approach to chronic disease management for the 21st century. London, Stationary Office.
- Hook M.L 2006 Partnering with patients- a concept ready for action. *Journal of Advanced Nursing*, 56 (2), 133-143.
- LTCAS 2008 Gaun Yersel' The Self Management Strategy for Long Term Conditions in Scotland. Scottish Government, Edinburgh. Available @ <http://www.scotland.gov.uk/Publications/2008/10/GaunYersel>, Accessed 10/9/10.
- LTCC 2010 Making the Connections- Food for thought. Edinburgh, Scottish Government.
- Scottish Executive (SE) 2007 Better Health Better Care. Edinburgh, Scottish Executive
- Scottish Government (SG) 2010 The Healthcare Quality Strategy for NHS Scotland Edinburgh, Scottish GovernmentSG
- 2009 Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan. HMSO
- Shaw J. Baker M. 2004 "Expert patient" Dream or Nightmare? *British Medical Journal* 328, 723. Available @ <http://www.bmj.com/content/328/7442/723.full> Accessed 29/9/10.
- Tyremans S 2005 An expert in what?: The need to clarify meaning and expectations in "The Expert Patient" Medicine, *Health Care Philosophy* 8,153-157.
- UK Research Integrity Office Procedure for the Investigation of Misconduct in Research available@ [http://www.ukrio.org/sites/ukrio2/the\\_programme\\_of\\_work/procedure.cfm](http://www.ukrio.org/sites/ukrio2/the_programme_of_work/procedure.cfm)
- WHO 1978 Primary Health Care, Report of the International Conference on Primary Health Care, Geneva WHO
- Wilson P.M. 2007 The Expert Patient: An Exploration of self-Management in Long Term Conditions PhD Thesis University of Hertfordshire.

### 3. PURPOSE AND DESIGN OF THE RESEARCH

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

**A7. Select the appropriate methodology description for this research. Please tick all that apply.**

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☒ Qualitative research
- ☐ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☒ Other (please specify)  
non participant observation

**A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.**

What strategies are used by young (aged 16-35) "expert patients" with Cystic fibrosis or Type 1 diabetes and healthcare professionals to maintain and negotiate partnership?

**A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.**

1. How do young "expert patients" and the healthcare professionals with whom they engage perceive partnership?
2. What are the perceived outcomes of partnership from the patients' and health care professionals' perspectives?
3. What are the perceived and observed factors that enable or inhibit partnership?
4. How do young "expert patients" report their use of past experiences of interactions with health care professionals to negotiate care management strategies in future encounters?

**A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.**

The concept of partnership between patients and Health Care Professionals (HCPs) is not new and is linked to the ethics of healthcare and the recognition that patients have rights and responsibilities to be involved in health care management and decisions (WHO 1978). The increased emphasis given to partnership approaches (particularly with regard to self management of LTCs) is evidenced by the language in policy documents emphasising empowerment of patients and "a mutual NHS" (DoH 2006, SE 2007, LTCAS 2008, LTCC 2010, DH 2010, SG 2010) and the increasing number of citations with regard to partnership in the health and social science literature (Hook 2006).

Partnership is said to involve relationship, shared decision making, power-sharing, patient autonomy, shared knowledge, participation, communication and professional competence. (Hook 2006). However published work in the last ten years highlights that this supposed shift towards partnership is often still rhetoric rather than reality; with nurses being involved in covert surveillance of clients, (Wilson 2001, 2007), and exerting power over carers (Henderson 2003, Coyne 2007a, 2007b). Many of these studies are small scale exploratory descriptive studies, but draw similar conclusions about the perceived lack of equality in partnership by patients and carers, despite the intent expressed in the literature. This area warrants further enquiry.

Other factors which would appear to have added to the need for patients and HCPs to work together are changing demographics and an increase in the number of people with a Long term Condition (LTC). In Scotland this accounts for

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

approximately 40% of its population (ISD 2008).

This rise in LTCs has also seen a shift towards self management: a concept which emerged from the USA in the 1990s following a short term randomised controlled trial of 952 patients with a variety of long term conditions (Lorig et al.1999). Those randomised to a community self management programme showed better exercise tolerance, less self-reported distress, better symptom management and fewer hospitalisations. Significant cost savings were noted between the treatment and control groups. However, patients were self selecting, suggesting that they were highly motivated anyway, and generally well educated. This may have implications for the generalisability to other populations. Further, follow up was only to 6 months post intervention; long term sustained improvements were therefore not evidenced.

The UK Expert Patient Programme (DoH, 2001) builds on the work of Lorig and has been one of many subsequent self management initiatives. Claims have been made as to the benefits of self management in terms of reduced use of resources, increased self confidence and self efficacy and improved symptom control. However, the evidence to support this remains inconclusive and studies have been criticised for their lack of long term evaluation, (Foster et al. 2007, Wilson 2007, Rogers 2009, Coster and Norman 2009, Greenhalgh 2009). Criticism has also been levelled at the way outcomes are measured in these programmes; in professional rather than patient terms, with more emphasis placed on biomedical outcomes by professionals (e.g.increase in lung function),as opposed to subjective improvement by patients (e.g.having increased energy levels)(Newbould et al. 2006, Rogers 2009). Patients may place a higher importance on social roles than symptom control,thus priorities in management of the LTC may differ between the patient and the professional. This may have a subsequent impact on the nature of partnership working and is an area of interest to the researcher which is felt warrants further exploration.

The term "expert patient" has evolved as a result of policy initiatives in self management(DoH 2001). There is much debate in the literature at the amorphous use of the term "expert patient" and the definition of expert(Tyremen 2005). Expertise is not a concept easily applied to both HCPs and patients and it would appear that the use of the term "expert patient" has invoked anxiety and discomfort among health care professionals who may feel threatened by its usage, (Shaw and Baker 2004, Daiki 2004, Corlett and Twycross 2006, Wilson 2007). It is proposed that this concept will be explored further with both parties in the study.

LTCs are often associated with midlife and old age. The researcher comes from a background of working with young people with a LTC (cystic fibrosis)and it is clear that expertise is also present in this group. Many are diagnosed at a young age and may have built up a repertoire of skills and knowledge which informs their self management. This is also true of young people with Type 1 diabetes (Alderson et al 2006), thus these two groups and the HCPs with whom they consult form the sample group for the proposed research.

This proposal links to the researcher's previous research which unearthed the concepts of the patient as expert and barriers to achieving partnership working. This area was felt to warrant further exploration; particularly in light of the policy initiatives of patient inclusion and partnership in health care and the debate around the term "expert patient". Thus the aim of this study is to explore what strategies are used by young "expert patients" with Cystic fibrosis or Type 1 diabetes and healthcare professionals to negotiate and maintain partnership?

Research Question;

What strategies are used by young "expert patients" with Cystic fibrosis or Type 1 diabetes and healthcare professionals to negotiate and maintain partnership working?

Sub questions:

- 1.How do young "expert patients" and the healthcare professionals with whom they engage perceive partnership?
- 2.What are the perceived outcomes of partnership from the patients' and health care professionals' perspectives?
- 3.What are the perceived and observed factors that enable or inhibit partnership?
- 4.How do young "expert patients" report their use of past experiences of Interactions with health care professionals to negotiate care management strategies in future encounters?

The proposal has been submitted and approved as part of a professional doctorate at Queen Margaret University Edinburgh

References

- Alderson P. Sutcliffe K. Curtis K. 2006. Children as partners with adults in their medical care. Archives of Disease in Childhood, 91, 300-304.
- Corlett J. Twycross A. 2006(a), Negotiation of parental roles within family- centred care; a review of the literature Journal of Clinical Nursing 15, 1308-1316
- Coster S. Norman I. 2009 Cochrane review of educational and self-management interventions to guide nursing practice; A review International Journal of Nursing Studies 46, 508-528



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

- Coyne I. 2007(a) Disruption of parent participation: nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing* 17, 3150-3158.
- Coyne I. 2007 (b) Challenging the philosophy of partnership with parents: A grounded theory study. *International Journal of Nursing Studies*, 44 893-904
- Daiki I. 2004 Changing nurse dis-empowering relationship patterns. *Journal of Advanced Nursing*, 48 (1), 43-50.
- Department of Health (DH) 2010 Equity and Excellence: Liberating the NHS London, HMSO.
- Department of Health (DoH) 2006 Our Health Our care: a new direction for community services DoH, London
- Department of Health(DoH) 2001 The Expert Patient- a new approach to chronic disease management for the 21st century. London, Stationary Office.
- Foster G. Taylor S.J. Eldridge S. Ramsay J. Griffiths C.J. 2007 Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews* (4), Henderson S. 2003 Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing* 12 (4), 501-508.
- Greenhalgh T. 2009 Patient and public involvement in chronic illness: beyond the expert patient *British Medical Journal* 338 (1048), 629-631.
- Henderson S. 2003 Power imbalance between nurses and patients: a potential inhibitor of partnership in care. *Journal of Clinical Nursing* 12 (4), 501-508.
- Hook M.L 2006 Partnering with patients- a concept ready for action. *Journal of Advanced Nursing*, 56 (2), 133-143.
- Lorig K. R. Sobel D. S. Stewart A. L. Brown, J. Bandura A. Ritter P. Gonzalez V. M. Laurent D. D. Holman H. R. 1999. Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization a randomized trial. *Medical Care* 37 (1), 5-14
- LTCAS 2008 Gaun Yersel' The Self Management Strategy for Long Term Conditions in Scotland. Scottish Government, Edinburgh. Available @ <http://www.scotland.gov.uk/Publications/2008/10/GaunYersel>, Accessed 10/9/10.
- LTCC 2010 Making the Connections- Food for thought. Edinburgh, Scottish Government.
- Newbould J. Taylor D. Bury M. 2006 "Lay-led self-management in chronic illness: a review of the evidence." *Chronic Illness* Dec;2 (4),249-61
- Rogers A. 2009 Advancing the expert patient? *Primary Health Care Research & Development* 10, 167-176.
- Scottish Executive (SE) 2007 Better Health Better Care. Edinburgh, Scottish Executive
- Scottish Government (SG) 2010 The Healthcare Quality Strategy for NHS Scotland Edinburgh, Scottish GovernmentSG
- 2009 Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan. HMSO
- Shaw J. Baker M. 2004 "Expert patient" Dream or Nightmare? *British Medical Journal* 328, 723. Available @ <http://www.bmj.com/content/328/7442/723.full> Accessed 29/9/10.
- Tyerman S 2005 An expert in what?: The need to clarify meaning and expectations in "The Expert Patient" *Medicine, Health Care Philosophy* 8,153-157.
- WHO 1978 Primary Health Care, Report of the International Conference on Primary Health Care, Geneva WHO
- Wilson P.M. 2007 The Expert Patient: An Exploration of self-Management in Long Term Conditions PhD Thesis University of Hertfordshire.
- Wilson H. V. 2001. Power and partnership: a critical analysis of the surveillance discourses of child health nurses. *Journal of Advanced Nursing*, 36 (2). 294-301.

**A13. Please summarise your design and methodology. It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.**

The proposed qualitative study seeks to explore the nature of partnership between young self perceived expert patients and Health Care Professionals (HCPs). It is thus essential that both parties' views are sought. This will be achieved through the use of non participant observation and semi structured interviews within a single case study design. Case study is an appropriate design when a "how" or why question is being asked about matters over which the researcher has no control and which are undertaken in real life situations. The single case study is the group of expert patients located from two patient groups, (CF and Type 1 diabetes) and the health professionals they encounter in their consultations.

Observation will take place in consultation settings in Out-Patients within a large Edinburgh teaching hospital between health professionals (e.g. nurses doctors, dieticians) and young (aged 16-35) "expert" patients with either CF or Type 1 diabetes. The observed consultation will be audio taped and transcribed word for word.

A single semi structured interview will be conducted after the observed consultation and will be the method used to discuss the experiences of partnership working and to unpick the observed consultation event. Interviews with HCPs will take place in their place of work, whilst interviews with patients may be held either in the out-patient setting or in the patients own home. HCPs and young expert patients will be interviewed separately and data will be audio taped and transcribed word for word. Field notes will be taken during the consultations and interviews to assist with the audit trail and to document the author's assumptions and possible biases. If a young expert patient sees more than one health professional per out-patient visit (as often happens at CF clinic, eg doctor, nurse, dietitian, physiotherapist), with their consent- each of these consultations will be observed and audio taped. However only one single interview will be conducted with each patient and each health professional which discusses the different observed consultations.

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

This is in order to minimise the patient becoming fatigued as well as making less demands on both the patient and the HCP's time. All participants have the right to opt in or out of the observed sessions (for example they may wish to opt out if they want to discuss issues of a sensitive nature without being observed). Further, participants- during interview- have the right to choose not to discuss something which the researcher raises that has been observed during the consultation. It is proposed to sample up to 10 young expert patients and the same number of HCP's between Oct 2011-June 2012.

**A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?**

- ☐ Design of the research
- ☐ Management of the research
- ☒ Undertaking the research
- ☒ Analysis of results
- ☒ Dissemination of findings
- ☐ None of the above

*Give details of involvement, or if none please justify the absence of involvement.*

This study links to previous research involving young people with CF and their carers. As the proposed study seeks to explore the nature of partnership between young people with a long term condition and Health professionals it is imperative that the young people have a voice and are involved in the study. It will be important for the rigour of the findings that a sample of the young people and HCPs are able to confirm the trustworthiness of the data, which will be achieved through member checking with a sample of participants. Finally it is courteous and good practice that those who are involved in the research should have access to the published findings and to achieve this a summary report will be produced for the whole sample group.

### 4. RISKS AND ETHICAL ISSUES

#### RESEARCH PARTICIPANTS

**A15. What is the sample group or cohort to be studied in this research?**

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases
- ☒ Diabetes
- ☐ Ear
- ☐ Eye
- ☐ Generic Health Relevance
- ☐ Infection
- ☐ Inflammatory and Immune System
- ☐ Injuries and Accidents
- ☐ Mental Health
- ☐ Metabolic and Endocrine
- ☐ Musculoskeletal
- ☐ Neurological
- ☐ Oral and Gastrointestinal



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

<input type="checkbox"/> Paediatrics <input type="checkbox"/> Renal and Urogenital <input type="checkbox"/> Reproductive Health and Childbirth <input checked="" type="checkbox"/> Respiratory <input type="checkbox"/> Skin <input type="checkbox"/> Stroke	
Gender:	Male and female participants
Lower age limit: 16	Years
Upper age limit: 35	Years

### A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

-Patients aged 16-35 years, of either gender, who speak English, with CF or Type 1 Diabetes who attend clinics in Edinburgh.  
 -Patients should have transitioned from a paediatric clinic or moved from another adult clinic over a year ago as it will be important that they have built up a relationship with the HCPs whom they encounter.  
 -Diagnosis of CF/IDDM which requires a significant amount of self management.(Some CF patients may also have diabetes- this would not exclude them as long as they have been managing one LTC for >5 yrs).  
 -Must have lived with the disease for 5 years or more (Suggests a level of experience of living with a LTC)  
 -Must attend a CF or Diabetic clinic in Edinburgh area (Logistics of travel and access for researcher)  
 -Views themselves or are viewed as expert patients- have to self manage a range of treatments (medicines/insulin/physiotherapy/diet)and use skills such as self monitoring, testing and adapting treatments using experiential knowledge.(Tyreman 2005).Patients may self select, and deselect as appropriate.  
 -Must attend at least 2 Consultations with diabetic/CF team per annum and have attended a consultation within 6 months, (suggests engagement with HCPs on a relatively regular basis).  
 -HCPs (nurses, doctors, physiotherapists, dietiticians, psychologists, pharmacists) should be working with patients with CF or Type 1 Diabetes in consultation settings).

### A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

**Exclusion Criteria**  
 -Patients who have been self managing for less than 5 years.  
 -patients out with the 16-35 age range.  
 -Patients who have transitioned from a paediatric clinic or another specialist centre within the past year.  
 -Patients who have not consulted with a HCP at least 6 monthly.  
 -Patients who do not understand or speak English.  
 -HCPs who do not consult with patients with CF or Type 1 Diabetes

## RESEARCH PROCEDURES, RISKS AND BENEFITS

### A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. These include seeking consent, interviews, non-clinical observations and use of questionnaires.

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

Intervention or procedure	1	2	3	4
seeking consent	3	1	30 mins	PI will conduct all of the interventions
observed clinical consultation				Interview 40 mins (home/OP Clinic)
semi structured interview				consent 15 mins (home/OP Clinic)
				observed clinic consult 15-30 mins (OP Clinic)

### A21. How long do you expect each participant to be in the study in total?

Data collection will span Oct 2011 -June 2012. The study is expected to be completed by June 2013. A sample of participants will be contacted during June 2012-13, to receive findings and give feedback. The sample should reflect the range of participants in the study.

### A22. What are the potential risks and burdens for research participants and how will you minimise them?

*For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.*

The perceived main ethical issues are:

1. Familiarity with staff in the CF unit which may create bias or make staff feel uncomfortable.
2. Raising of sensitive issues which patients may feel will threaten the therapeutic relationship and impact on care.
3. Loss of confidentiality- between patients and HCPs if data is shared between them- and in general through presentation of results and inappropriate storage of data.
4. Issues of gaining informed consent of patients.
5. Observation of poor practice by the researcher during a consultation.

Issues and proposed measures to address them

1. The researcher worked in the CF unit some years ago and some of the staff (and possibly one or two of the patients) are known to her. Familiarity with staff may influence normal activity; for example HCPs may feel uncomfortable being observed by a former colleague and may behave differently.

The researcher will meet with staff to discuss the proposed study (pending ethical approval) and will spend some time in the out-patients department with the team during the recruitment phase which may help to break down any perceived barriers. The team are used to having observers, "sit in" in clinic consultations as part of their educative roles in a large teaching hospital. The role of the researcher is not to be judgemental but to observe and record the observed event. However the researcher has an awareness of subjectivity in research and this will be noted and discussed with research supervisors throughout the research process through the use of reflection and field notes.

2. Service users who are critical of the service may be hesitant in expressing these views for fear of offending individual HCPs and subsequently altering the relationship or the care that exists between them. This may occur through a perceived potential loss of confidentiality.  
It will be stressed that participation in this study will be entirely voluntary and participants have the right to refuse to take part or withdraw from the study at any time without having to give a reason. All participants have the right to opt in or out of the observed sessions (for example they may wish to opt out if they want to discuss issues of a sensitive nature without being observed). Further, participants- during interview- have the right to choose not to discuss something of a sensitive nature which the researcher raises that has been observed during the consultation.  
A contact person (Senior Lecturer at QMU) not associated with the research has been identified should participants wish to raise any issues associated with the research process. This person will be named on the information sheet but the researcher will raise this again at each interview to ensure participants are fully informed of the support available. Additionally participants have access to NHS complaints procedure and this is detailed on the information sheet (Appendices 1,2).

3. To ensure confidentiality, Identifiers will be coded (voice, context, role, personal perspective) so that data presented

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

in the final report are anonymous to readers and other participants. The small numbers in the study make it likely that HCP's and patients may recognise who has said what when questioned at interview (after the observed event) but names and identities will not be divulged between individuals and data will be presented in such a way that patients and the health professionals they consult with are not linked (i.e. coded).

The Principal Investigator will assume responsibility for security of data collected. Coded data will be entered into a computer base at QMU. All interviews will be recorded on tape. Tapes will be transcribed verbatim. Tapes and coded data will be stored in a locked cabinet. Files stored on computer are password protected. The only other people who will have access to transcripts will be doctoral supervisors who will be unaware of identities. All raw data will be stored in accordance with QMU Retention Policy which is informed by the Data Protection Act (1998). Raw data will be stored for 5 years on completion of the research, initially on campus and then in remote secure storage. Signed consent forms will be stored separately from the data for 12 months on campus, thereafter remotely in secure storage for the duration of the retention of the raw data. The results of this project will be disseminated at various conferences and meetings and in peer reviewed journals. Direct quotations will be used in reports and publications and presented in a way to secure participant anonymity (using codes and pseudonyms).

4. Participants will be asked to provide their written informed consent prior to the consultation event and interview. Participants may choose to take part in only the interview or the observation event (as opposed to both), and that is their right. Participation is voluntary and participants have the right to refuse to take part or withdraw from the study at any time without having to give a reason. Withdrawal will not impact on their future management. Patients with a LTC can be at risk of "research fatigue" as they are often of interest to many different researchers. Additionally their health issues may impact on their ability to participate in research perhaps due to ill health or time constraints. It is important therefore that participants do not feel coerced into research studies and thus no pressure will be placed upon them to do this.

5. Theoretically, observation may raise issues of poor practice; however the researcher is aware that the health professionals under observation are experienced practitioners who hold fairly senior positions (e.g. Registrars, Nurse Specialists). However should this issue arise the researcher would address this with her research supervisors in the first instance and thereafter through the appropriate channels. If at interview patients were to report poor practice regarding HCPs, they would be advised by the researcher to report this through the normal NHS Complaints Procedure.

As an employee and student of QMU, the researcher will adhere to the highest professional standards of scientific integrity by abiding by the laws and ethical principles outlined below.

As a recipient of public funding, the University must have the confidence of both the general public and those organisations responsible for funding specific research projects. All staff are required to adhere to the University's Code of Research Practice which is available on our website. The University is committed to Research Governance in terms of setting standards to improve research quality and safeguard the public. In all its research and associated activity it aims to ensure ethical and scientific quality, promoting good practice, reducing adverse incidents, ensuring lessons are learned and preventing poor performance and misconduct. It is about both continuous quality improvement and being accountable for quality improvement. Clinical governance provides a framework to co-ordinate quality improvement and quality control and its effects on the research and commercial activities undertaken by the University and its staff. It is an umbrella for a range of activities that aim to promote, maintain and improve standards of patient care. Clinical governance is of great importance to all healthcare professionals. QMU adheres to the UK Research Integrity Office Procedure for the Investigation of Misconduct in Research.

### References

Data Protection Act 1998 London, HMSO.

Tyreman S 2005 An expert in what?: The need to clarify meaning and expectations in "The Expert Patient" Medicine, Health Care Philosophy 8, 153-157.

UK Research Integrity Office Procedure for the Investigation of Misconduct in Research available @ [http://www.ukrio.org/sites/ukrio2/the\\_programme\\_of\\_work/procedure.cfm](http://www.ukrio.org/sites/ukrio2/the_programme_of_work/procedure.cfm)

**A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?**

☒ Yes ☐ No

*If Yes, please give details of procedures in place to deal with these issues:*

A named person not connected with the research is available should participants become distressed or concerned about sensitive issues. Additionally participants (patients) have access to the NHS complaints procedure and this is detailed on the information sheet, (Appendices 1,2).

The researcher has experience of interviewing participants in potentially sensitive situations. All possible measures



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

to assure confidentiality and promote anonymity will be taken,(see A22).Participants have the right to withdraw at any stage of the process without affecting their status as patients and this will be made clear during the consent process. Disclosures from either patients or HCPs that indicate distress will be discussed with supervisors in the first instance and thereafter channelled through the appropriate procedures or support structures; (e.g. NHS complaints, Occupational Health, NHS PALS Service).

### A24. What is the potential for benefit to research participants?

Whilst participants may not gain immediate benefit from the research, findings from the interviews and observations may highlight areas of practice (good or bad) that can be used to inform future practice. The principle of beneficence embraces the obligation to provide the benefits for the patient and health care professionals to undertake the study. Non maleficence requires that the researcher should do no harm and should prevent or remove already existing harm. However some patients may find participation in an interview an emotionally tiresome encounter as they may be discussing aspects of their care which may cause emotional upset. The researcher will inform patients that they can withdraw from the research at any time and if they find questions stressful then they have an opportunity to discuss this with the named external person in the research proposal. The researcher will use sensitive questioning skills such as listening, attending, reflecting and summarizing back key elements of the participant's responses. Should HCPs become distressed they have the same rights as patients to withdraw at any time and may contact the named person who is independent of the research. Additionally they have access to support through the NHS (e.g occupational Health, NHS PALS Service).

<http://www.pals.nhs.uk/cmsContentView.aspx?ItemID=933>

### A26. What are the potential risks for the researchers themselves? (if any)

The researcher may be involved in interviewing participants in their own homes. Should this be a lone interview then the supervisors will be notified of where and when the visit is taking place and the researcher will telephone the supervisor on completion of the interview. Should the supervisor fail to receive a call from the researcher then they will initiate contact by mobile phone. QMU has a lone worker policy which will be used to inform this process.

## RECRUITMENT AND INFORMED CONSENT

*In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.*

### A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).

The term "expert patient" is poorly defined and understood. Recruiting young "expert patients" will therefore be assumed to be challenging in this study. It is proposed that once ethical approval is gained, the PI will visit the specialist Diabetic and CF teams to discuss the meaning of an "expert patient" for purposes of recruitment. Tyreman's (2005) criteria(Appendix 7),will be the basis for defining the sample of patients in the proposed study, however it is also hoped that patients may self select based upon the posters,adverts and information leaflets used in the recruitment process. Specialist nurses will be asked to help identify which patients meet the inclusion criteria but it is not the intention that they choose which patients should be recruited as this would introduce bias into the study;(for example should they choose only popular patients).

A two stage recruitment strategy is proposed

Stage 1: patients will be identified through newsletters, (e.g. Diabetes UK, LTCAS, Butterfly Trust), posters (in specialist OP clinics), and via Specialist Nurses. Information leaflets about the proposed research will be available, (Appendix 1). Interested parties will then be followed up with letters of invitation to further advise of the proposed study and seek written consent for participation (Appendix 3).

Stage 2: On agreement to participate, patients will then be asked to identify the health professionals they encounter in their regular consultations as part of the management of their LTC. These professionals will then be approached (by letter- Appendix 2) and invited to participate in the study. Their written consent will be sought on agreement of participation (Appendix 4).

Patients medical records need not be accessed during this study. All data handled and stored as part of the research study will be managed as per QMU Retention policy and Data Protection Act 1998, (see section A22)

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

**A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?**

☐ Yes ☒ No

*Please give details below:*

**A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?**

☒ Yes ☐ No

*If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).*

A two stage recruitment strategy is proposed:

Stage 1: Posters will be displayed in patient waiting areas in specialist out-patient clinics and adverts placed in newsletters, (e.g. Diabetes UK, LTCAS, Butterfly Trust). If potential participants are interested in receiving further information on the proposed study they should contact the researcher via the contact details on the posters and information sheets. At this stage personal or e-mail addresses will be required in order that information can be sent to participants by the researcher. The researcher will then issue information packs (containing an information sheet, consent form and stamped addressed envelope; appendices 1-4). On receipt of packs participants will be given one week to decide whether to opt into the study and post back forms, or e-mail or telephone the researcher. Reminder letters can then be sent out to those participants who have not made contact after one week.

Additionally Specialist Nurses will be made aware of the study and may also issue packs if patients express an interest to them. Information leaflets about the proposed research will be also be available at the out-patient clinics and the researcher will be in attendance at some of these clinics in order to answer any potential questions.

Stage 2: On agreement to participate, patients will then be asked to identify the health professionals they encounter in their regular consultations as part of the management of their LTC. These professionals will then be approached (by letter or e mail- Appendix 2) and invited to participate in the study. Professionals will not be given the identity of the patient who identified them as one of the health care professionals whom they consult with. Their written consent will be sought on agreement of participation (Appendix 4).

**A29. How and by whom will potential participants first be approached?**

see above. If Participants express an interest through the posters and adverts (A28) they can approach the researcher who will be available at the out-patient settings to give out leaflets and answer questions related to the study. In addition the researcher will ask for the assistance of Nurse Specialists to hand out leaflets and packs at clinics where the researcher cannot be present. Information packs will contain contact details of the researcher (e-mail, telephone number). HCP's will be approached by letter or e-mail once they have been identified by a patient. Participants will be invited to contact the researcher for further information (rather than the other way around) so that no undue coercion is placed on any of the potential participants.

**A30-1. Will you obtain informed consent from or on behalf of research participants?**

☒ Yes ☐ No

*If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.*

*If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.*

If potential participants contact the researcher to state an interest in the study, an information pack will be given to them at the out-patients or sent by post. This will contain, a leaflet outlining the research and a consent form (Appendices 1,3) with a stamped address envelope, which should be returned to the researcher. The form will also ask patients to identify which HCPs they consult with and their corresponding place of work.

These HCPs will be approached by letter, or e-mail, and information packs sent inviting them to participate in the study. It is proposed that before any recruitment begins the researcher will attend one each of the CF and diabetic team meetings once ethical approval is gained to discuss the study with the HCPs. Young people with a LTC may be classed as vulnerable as they may feel that not to participate may impact on their care. Additionally their health may place them in a vulnerable position (e.g. if they do not feel well enough to participate on the day, or have time constraints). It will be made clear that participation is voluntary and they have the right to withdraw at any time without impact on their relationship with HCPs or care provided.

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

*If you are not obtaining consent, please explain why not.*

*Please enclose a copy of the information sheet(s) and consent form(s).*

**A30-2. Will you record informed consent (or advice from consultees) in writing?**

☒ Yes ☐ No

**A31. How long will you allow potential participants to decide whether or not to take part?**

Once Information packs (Appendices 1-4) have been sent out participants will be given one week to return them. This will allow participants time to read the information and make a decision regarding their participation. Reminder letters will be sent out after this time, inviting patients and HCPs to participate.

**A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)**

Although there is some availability of interpreters and translators within the NHS, language difficulties are not expected as a matter of course. The study has small numbers of participants and should this issue arise for any of the participants, the researcher will seek advice from the professional/practitioner involved on an individual case basis. The study has no funding for translation or use of interpreters. However this might be seen as a potential limitation of the study.

**A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.**

- ☒ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- ☐ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- ☐ The participant would continue to be included in the study.
- ☐ Not applicable – informed consent will not be sought from any participants in this research.
- ☐ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

*Further details:*

### CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

### Storage and use of personal data during the study

**A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?(Tick as appropriate)**

- ☐ Access to medical records by those outside the direct healthcare team
- ☐ Access to social care records by those outside the direct social care team
- ☐ Electronic transfer by magnetic or optical media, email or computer networks
- ☐ Sharing of personal data with other organisations



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

- ☐ Export of personal data outside the EEA
- ☒ Use of personal addresses, postcodes, faxes, emails or telephone numbers
- ☒ Publication of direct quotations from respondents
- ☒ Publication of data that might allow identification of individuals
- ☒ Use of audio/visual recording devices
- ☐ Storage of personal data on any of the following:
  - ☒ Manual files (includes paper or film)
  - ☐ NHS computers
  - ☐ Social Care Service computers
  - ☐ Home or other personal computers
  - ☒ University computers
  - ☐ Private company computers
  - ☐ Laptop computers

**Further details:**

Personal addresses, e-mails and telephone numbers will only be known to the researcher and will be locked in a secure place on QMU premises.

Telephone numbers may be asked for, in order to:

\*Contact participants to set up dates and times for observation and interviews.

\*Contact key professionals for the same purpose.

Audio recording devices will be used with permission of participants and it will be stressed that use will be only for purposes of data analysis.

Direct quotations will be used in reports and publications and presented in a way to secure participant anonymity (i.e. coded and pseudonyms used).

Tapes will be securely locked within QMU premises and will be stored with other coded material as per QMU Retention Policy.

Personal identifiers will only be known to the researcher.

The researcher will comply with all aspects of Research Governance and management approval from R & D will be sought. The researcher has enhanced disclosure from the Scottish Criminal Record Office. Records of meetings with experienced supervisors will be kept to ensure a clear audit trail and adherence to research governance.

**A37. Please describe the physical security arrangements for storage of personal data during the study?**

Identifiers will be coded (voice, context, role, personal perspective) so that data presented in the final report is anonymous to readers and other participants. The Principal Investigator will assume responsibility for security of data collected. Coded data will be entered into a computer base at QMU. All interviews will be recorded on audio tape and transcribed verbatim. Tapes and coded data will be stored in a locked cabinet in the university. Files stored on computer (within the university) are password protected. The only other people who will have access to transcripts will be doctoral supervisors who will be unaware of identities. All raw data will be stored in accordance with QMU Retention Policy which is informed by the Data Protection Act (1998). Raw data will be stored for 5 years on completion of the research, initially on campus and then in remote secure storage. Signed consent forms will be stored separately from the data for 12 months on campus thereafter remotely in secure storage for the duration of the retention of the raw data.

**A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.**

Identifiers will be coded (voice, context, role, personal perspective) so that data presented in the final report is anonymous to readers and other participants. The results of this project will be disseminated at various conferences and meetings and in peer reviewed journals. Direct quotations will be used in reports and publications and presented in a way to secure participant anonymity. (use of codes and pseudonyms).

**A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.**

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

The only people who will have access to the data are the PI, and her three supervisors. All data will be coded after transcription and thus will be anonymised to the supervisors. Participants who are asked to verify data to increase rigour will only be asked to scrutinise their own data. All data will be coded and personal identifiers (names, place names removed).

### Storage and use of data after the end of the study

#### A41. Where will the data generated by the study be analysed and by whom?

The data will be analysed by the PI at Queen Margaret University. The PI will be supported by 3 supervisors who will have access to anonymised data for the purpose of supervision. All data will be held on a computer at Queen Margaret University which is password protected and firewalled.

#### A42. Who will have control of and act as the custodian for the data generated by the study?

	Title Forename/Initials Surname
	Mrs Kath MacDonald
Post	Lecturer in Nursing
Qualifications	RGN. MSc, PG cert Ed.
Work Address	Queen Margaret University Queen Margaret University Drive Musselburgh
Post Code	EH21 6UU
Work Email	kmacdonald@qmu.ac.uk
Work Telephone	01314740000
Fax	01314740001

#### A43. How long will personal data be stored or accessed after the study has ended?

- ☐ Less than 3 months
- ☐ 3 – 6 months
- ☐ 6 – 12 months
- ☐ 12 months – 3 years
- ☒ Over 3 years

*If longer than 12 months, please justify:*

All data will be stored as per QMU Retention Policy which is informed by the Data Protection Act (1998). Raw data will be stored for 5 years on completion of the research, initially on campus and then in remote secure storage. Signed consent forms will be stored separately from the data for 12 months on campus thereafter remotely in secure storage for the duration of the retention of the raw data.

#### A44. For how long will you store research data generated by the study?

Years: 5  
Months:

#### A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

see A43



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

The PI will have have responsibility for access, storage and destruction of raw data. Data will be destroyed 5 years after completion of the research.

### INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

☐ Yes ☒ No

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

☐ Yes ☒ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

☐ Yes ☒ No

### NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

☒ Yes ☐ No

*If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.*

A49-2. Will you seek permission from the research participants to inform their GP or other health/ care professional?

☒ Yes ☐ No

*It should be made clear in the participant's information sheet if the GP/health professional will be informed.*

### PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

☒ Yes ☐ No

*Please give details, or justify if not registering the research.*

Any outputs from the research will be registered on the QMU Academic Research Database.

Additionally outputs which appear as conference proceedings or in peer reviewed scholarly articles will be able to be accessed via library databases such as CINAHL.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- ☒ Peer reviewed scientific journals
- ☒ Internal report
- ☒ Conference presentation
- ☒ Publication on website

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

**A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?**

all raw data will have personal identifiers removed in order to protect anonymity. Direct quotations will be used in reports and publications and presented in a way to secure participant anonymity, by using codes and pseudonyms.

**A53. Will you inform participants of the results?**

☒ Yes ☐ No

*Please give details of how you will inform participants or justify if not doing so.*

A summary report and a thank you letter will be produced and sent to all participants in the study in order that they receive feedback on the study. A sample of participants will be asked to member check their own data for the purpose of veracity of the research.

### 5. Scientific and Statistical Review

**A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:**

- ☒ Independent external review
- ☐ Review within a company
- ☐ Review within a multi-centre research group
- ☒ Review within the Chief Investigator's institution or host organisation
- ☐ Review within the research team
- ☒ Review by educational supervisor
- ☐ Other

*Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:*

All doctorate students undergo regular review with supervisors and Director of studies. In addition the research proposal has been submitted to Queen Margaret University as a doctoral proposal and has been subject to review, feedback and support from the Director of studies, supervisors, head of Doctoral research at the institution and an external examiner.

*For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.*

*For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.*

**A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.**

Total UK sample size: 20

Total international sample size (including UK):

Total in European Economic Area:

*Further details:*

The proposed achieved sample of 20 participants will comprise 10 young expert patients and 10 Health care

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

Professionals who are involved in the care of these patients.

**A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.**

Qualitative research does not aim to be yield results that are generalisable or statistically significant. The researcher will use purposive sampling as this type of sampling will identify a specific population of interest (young "expert patients" and the HCPs with whom they interact). Purposive sampling looks at a certain range of respondents but will include one or two negative or deviant cases (Silverman 2005)- those who do not fit the label of expert patient- in order to test rival explanations made about this group. In discussion with supervisors, the sample size is chosen on pragmatic judgement based on the scope of the study, the timescale and the resources available;thus 20 is the proposed achieved sample.

Reference:(Silverman D 2005 Doing Qualitative Research London,Sage.

**A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.**

The methods of analysis will be an ongoing and iterative process analysing scripts from each participant before moving onto the next.The method of analysis will be qualitative thematic analysis, which involves coding the characteristics of what is being said and observed, giving codes to themes and seeing a pattern developing (Ritchie and Lewis 2003). The analytical strategies in case study design involve pattern matching of themes, the identification of rival explanations in data and explanation building(Yin 2009, Stake 1995).The researcher will use a software computer package, (N Vivo8) to organise the data and build themes. The researcher will also add reflective and field notes throughout the analysis to demonstrate transparency and veracity in the data collection process.

#### References

Ritchie J Lewis J (2003) Qualitative Research Practice: A Guide for Social Science

QRR (undated)NVivo8 Available@<http://www.qsrinternational.com/FileResourceHandler.aspx/RelatedDocuments/DocumentFile/289/NVivo8-Getting-Started-Guide.pdf> Accessed 23/6/11

Stake R.E. 1995 The Art of Case Study Research London, Sage.

Yin R. K. 2009 Case study Research 4th Ed. London, Sage.

### 6. MANAGEMENT OF THE RESEARCH

**A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.**

Title Forename/Initials Surname

Post

Qualifications

Employer

Work Address

Post Code

Telephone

Fax

Mobile

Work Email

**A64. Details of research sponsor(s)**

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### A64-1. Sponsor

#### Lead Sponsor

Status: ☐ NHS or HSC care organisation    Commercial status: Non-Commercial  
☒ Academic  
☐ Pharmaceutical industry  
☐ Medical device industry  
☐ Other

*If Other, please specify:*

#### Contact person

Name of organisation Queen Margaret University  
Given name Dr Kathy  
Family name Munro  
Address QMU  
Town/city Musselburgh  
Post code EH21 6UU  
Country UNITED KINGDOM  
Telephone 01314740000  
Fax 01314740001  
E-mail kmunro@qmu.ac.uk

#### Is the sponsor based outside the UK?

☐ Yes    ☒ No

*Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.*

### A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders  
☐ External funding application to one or more funders in progress  
☒ No application for external funding will be made

### A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.

☐ Yes    ☒ No

### A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

☐ Yes    ☒ No

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68. Give details of the lead NHS R&D contact for this research:

	Title Forename/Initials Surname
	Dr Tina McLelland
Organisation	NHS Lothian
Address	Research & Development
	Queen's Medical Research Institute
	47 Little France Crescent
Post Code	EH164TJ
Work Email	R&DOffice@luht.scot.nhs.uk
Telephone	0131 242 3330
Fax	01312423343
Mobile	

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/10/2011

Planned end date: 01/06/2013

Total duration:

Years: 1 Months: 8 Days:

A71-1. Is this study?

- ☒ Single centre  
☐ Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

- ☐ England  
☒ Scotland  
☐ Wales  
☐ Northern Ireland  
☐ Other countries in European Economic Area

Total UK sites in study 1

Does this trial involve countries outside the EU?

- ☐ Yes ☒ No

A72. Which organisations in the UK will host the research? Please indicate the type of organisation by ticking the box and give approximate numbers if known:

- ☐ NHS organisations in England  
☐ NHS organisations in Wales  
☒ NHS organisations in Scotland

1

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

- ☐ HSC organisations in Northern Ireland
- ☐ GP practices in England
- ☐ GP practices in Wales
- ☐ GP practices in Scotland
- ☐ GP practices in Northern Ireland
- ☐ Joint health and social care agencies (eg community mental health teams)
- ☐ Local authorities
- ☐ Phase 1 trial units
- ☐ Prison establishments
- ☐ Probation areas
- ☐ Independent (private or voluntary sector) organisations
- ☐ Educational establishments
- ☐ Independent research units
- ☐ Other (give details)

Total UK sites in study:

1

**A73-1. Will potential participants be identified through any organisations other than the research sites listed above?**

☐ Yes ☒ No

**A74. What arrangements are in place for monitoring and auditing the conduct of the research?**

The PI will receive ongoing support and supervision from her three supervisors, and is expected to submit draft progress reports to feedback on the progress of the research and any issues that may arise. A senior Lecturer at the institution who is not involved with the research has volunteered to be named as a contact person to whom any of the participants can report, should the need arise. The researcher will also submit an application to QMU Research Ethics Committee which meets monthly. An application has also been submitted to NHS R&D. The researcher will be seeking an honorary contract in order to carry out data collection in the NHS site.

**A76. Insurance/ indemnity to meet potential legal liabilities**

*Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland*

**A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.**

*Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (NHS sponsors only)
- ☒ Other insurance or indemnity arrangements will apply (give details below)

Relevant documents enclosed.

Queen Margaret University holds public liability insurance which covers against claims of negligent harm as a direct consequence of participating in research studies (enclosed). The study will not commence until management approval from R&D (Lothian) is confirmed. The development and conduct of the study will be monitored by the research supervisors, and minutes of meetings, midway and final reports will be presented throughout the research process.

The researcher will

comply with all aspects of Research Governance and management approval from R & D will be sought. The researcher has enhanced disclosure from the Scottish Criminal Record Office.



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

Please enclose a copy of relevant documents.

**A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.**

*Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.*

- ☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)  
☒ Other insurance or indemnity arrangements will apply (give details below)

QMU has in place policies of employers' and public liability and professional indemnity insurance which covers against claims of negligent harm as a direct consequence of participating in research studies (enclosed). Documents are enclosed. The research proposal has been subject to scrutiny from internal supervisors and an external examiner.

Please enclose a copy of relevant documents.

**A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?**

*Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.*

- ☒ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)  
☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

QMU has in place policies of employers' and public liability and professional indemnity insurance for its own staff. They expect all collaborators to have similar levels of cover in place for staff.

Please enclose a copy of relevant documents.

**A78. Could the research lead to the development of a new product/process or the generation of intellectual property?**

☐ Yes ☒ No ☐ Not sure

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

23. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Patients aged 16-35 years, of either gender, who speak English, with CF or Type 1 Diabetes who attend clinics in Edinburgh.
- Patients should have transitioned from a paediatric clinic or moved from another adult clinic over a year ago as it will be important that they have built up a relationship with the HCPs whom they encounter.
- Diagnosis of CF/IDDM which requires a significant amount of self management,(Some CF patients may also have diabetes- this would not exclude them as long as they have been managing one LTC for >5 yrs).
- Must have lived with the disease for 5 years or more (Suggests a level of experience of living with a LTC)
- Must attend a CF or Diabetic clinic in Edinburgh area (Logistics of travel and access for researcher)
- Views themselves or are viewed as expert patients- have to self manage a range of treatments (medicines/insulin/physiotherapy/diet)and use skills such as self monitoring, testing and adapting treatments using experiential knowledge.(Tyreman 2005).Patients may self select, and deselect as appropriate.
- Must attend at least 2 Consultations with diabetic/CF team per annum and have attended a consultation within 6 months, (suggests engagement with HCPs on a relatively regular basis).
- HCPs (nurses, doctors, physiotherapists, dietiticians, psychologists, pharmacists) should be working with patients with CF or Type 1 Diabetes in consultation settings).



## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.

Research site		Investigator/ Collaborator/ Contact	
Institution name	Western General Hospital	Title	mrs
Department name	Out patients clinic	First name/	
Street address	Crewe Rd	Initials	Kath
Town/city	Edinburgh	Surname	MacDonald
Post Code	EH4 2XU		

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### PART D: Declarations

#### D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.
2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.
3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.
4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.
5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.
6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.
7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.
8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.
9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:
  - Will be held by the main REC or the GTAC (as applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
  - May be disclosed to the operational managers of review bodies, or the appointing authority for the main REC, in order to check that the application has been processed correctly or to investigate any complaint.
  - May be seen by auditors appointed to undertake accreditation of RECs.
  - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.
11. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication(Not applicable for R&D Forms)

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

- ☒ Chief Investigator  
☐ Sponsor  
☐ Study co-ordinator

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

- ☐ Student
- ☐ Other – please give details
- ☐ None

**Access to application for training purposes (Not applicable for R&D Forms)**

*Optional – please tick as appropriate:*

☒ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

Signature: .....

Print Name: Kath MacDonald

Date: 15/06/2011 (dd/mm/yyyy)

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### D2. Declaration by the sponsor's representative

*If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.*

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.
2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.
3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.
4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.
5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.
6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.
7. I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Signature: .....

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

## APPENDIX 15 (Contd)

Full Set of Project Data

IRAS Version 3.1

### D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.
2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.
3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.
4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

#### Academic supervisor 1

Signature: .....

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

#### Academic supervisor 2

Signature: .....

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

#### Academic supervisor 3

Signature: .....

Print Name:

Post:

Organisation:

Date: (dd/mm/yyyy)

## APPENDIX 16: Letter of approval for study

South East Scotland Research Ethics Committee 01  
Waverley Gate  
2 - 4 Waterloo Place  
Edinburgh  
EH1 3EG

19 August 2011

Mrs Kath MacDonald  
Lecturer in Nursing  
Queen Margaret University  
School of Health Sciences  
Division of Nursing, OT & AT  
EH21 6UU

Dear Mrs MacDonald

**Study title:** Negotiating healthcare through partnership: Exploring social interactions between Health Care Professionals and young "expert" patients in the self management of a long term condition (CF/Type 1 diabetes).  
**REC reference:** 11/SS/0001  
**Protocol number:** RTT153481 (Policy no )

Thank you for your letter of 02 August 2011, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC at a meeting held on 18 August 2011. A list of the sub-committee members is attached.

### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

### Ethical review of research sites

#### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Non-NHS sites

### Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- Change "tick" to "initial" the boxes on the consent form

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

## APPENDIX 16 (Contd)

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation.**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Advertisement	1	02 June 2011
Covering Letter		
Covering Letter		
Evidence of insurance or indemnity		
GP/Consultant Information Sheets	1	02 June 2011
Interview Schedules/Topic Guides	1	02 June 2011
Investigator CV		
Other: observation framework	1	02 June 2011
Other: tyeman expert patient criteria	1	02 June 2011
Other: return slip		
Other: Calgary		02 August 2011
Participant Consent Form	2	02 August 2011
Participant Information Sheet	2	02 August 2011
Protocol		10 December 2003
REC application		01 July 2011
Response to Request for Further Information		02 August 2011

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

## APPENDIX 16 (Contd)

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

<b>11/SS/0001</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

With the Committee's best wishes for the success of this project

Yours sincerely

**Dr Janet Andrews**  
**Chair**

Email: [emily.oconnor@nhslothian.scot.nhs.uk](mailto:emily.oconnor@nhslothian.scot.nhs.uk)

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: Dr Kathy Munro  
Dr Tina McLelland, NHS Lothian

### **South East Scotland Research Ethics Committee 01**

#### **Attendance at Sub-Committee of the REC meeting on 18 August 2011**

#### **Committee Members:**

Name	Profession	Present	Notes
Dr Janet Andrews	Associate Specialist	Yes	

#### **Also in attendance:**

Name	Position (or reason for attending)
Dr Alex Bailey	Scientific Officer
Ms E Pendleton	



## **APPENDIX 17: E-mail verification from peer reviewers**

Dear Kath

This is an email to confirm we have reviewed the qualitative work of Kath MacDonald. Specifically we reviewed the research questions, patient 7 transcript, the charting of P7 and Theme 1.1 Barriers to partnership. We reviewed these independently and on later discussion found a high consensus of agreement with quotes according to theme 1.1.

As feedback for Kath we have addressed the following issues:

- We asked Kath to explain how parental surveillance was perceived as a barrier, Kath explained this theme was a barrier to the patient becoming more independent and could lead to extreme situations such as not wanting to change medication. We are now in agreement with Kath that this subtheme is relevant within the main theme.
- Theme 1.1.2 we asked Kath to move P2 and P7 quotes to theme 1.1.8 – she agreed.
- 1.1.4: We asked for an expansion of the quote by P1 in order to provide further evidence, we highlighted P7 quote could be interpreted as an enabler to the partnership not a barrier, it was noted P7 also provided evidence for quote 2 within 1.1.18.
- 1.1.6: P7 quote was noted as an enabler not a barrier.
- 1.1.10: P7 quote also relevant to power dynamic. P7 also mentioned in transcript an agenda of information to gather within the consultation, dismissing information that was deemed irrelevant i.e. outside of the patient agenda.
- 1.1.11 we asked for a definition of this theme in order further understand the relevance, from Kath's explanation we are both in agreement this theme is relevant. It was also noted that any patient emotion was dealt with by the CNS, and this was seen as the norm that emotion has no place within the consultation environment.
- We fully agreed with themes 1.1.3, 1.1.5, 1.1.7, 1.1.18, 1.1.9,

We hope this helps and wish you all the best!  
Sarah Shepherd & Sarah Scott.

P.S. Attached is the chapter I was talking about, at the end of the chapter is a model that illustrates the consultation dynamic, they separate the needs of the patient into cognitive and affective, so within the consultation the patient has the need to 'know and understand' (cognitive) but also has the need to 'feel known and understood' (emotional). It is up to the clinician to enable both of these needs to be addressed.

**Sarah Shepherd**  
**PhD Student, Coventry university**  
**Patient Information Navigation**

## APPENDIX 18: E-mail verification from participant

7/8/12

Hello

how are you?

As promised here's a copy of your transcript which I've dictated word for word, from our interview. Can you have a wee look and confirm that it's an accurate account of our meeting?

The other document is the next part of the research process which looks at what we call the raw data (your interview) and tries to make some sense of it- (the analysis).

So what I've tried to do are draw some themes out of all the 22 interviews that I did and show in the attached where your account fits into this. So for example some of the major themes are

"experiences of partnership", which sub divide into "enablers" and "barriers" to partnership. Another theme is called "constructions of illness" which is about how people see themselves and cope with their condition.

Guess on this one I just need you to check that I'm not completely off beam and if I am let me know where!!

I really appreciate you doing this for me.

It adds to the Quality assurance process when it comes to me having to defend the thesis in front of an examiner. So its about convincing them that my interpretation is correct, not just all in my head, and having someone verify that (you!).

Any questions, come back to me, hope this all makes sense.

Please be assured that you will not be named or identified when this is published. All the results and quotes will be mixed up so that no one will know who said what!

Best regards

Kathy

8/8/12

Hi Kath

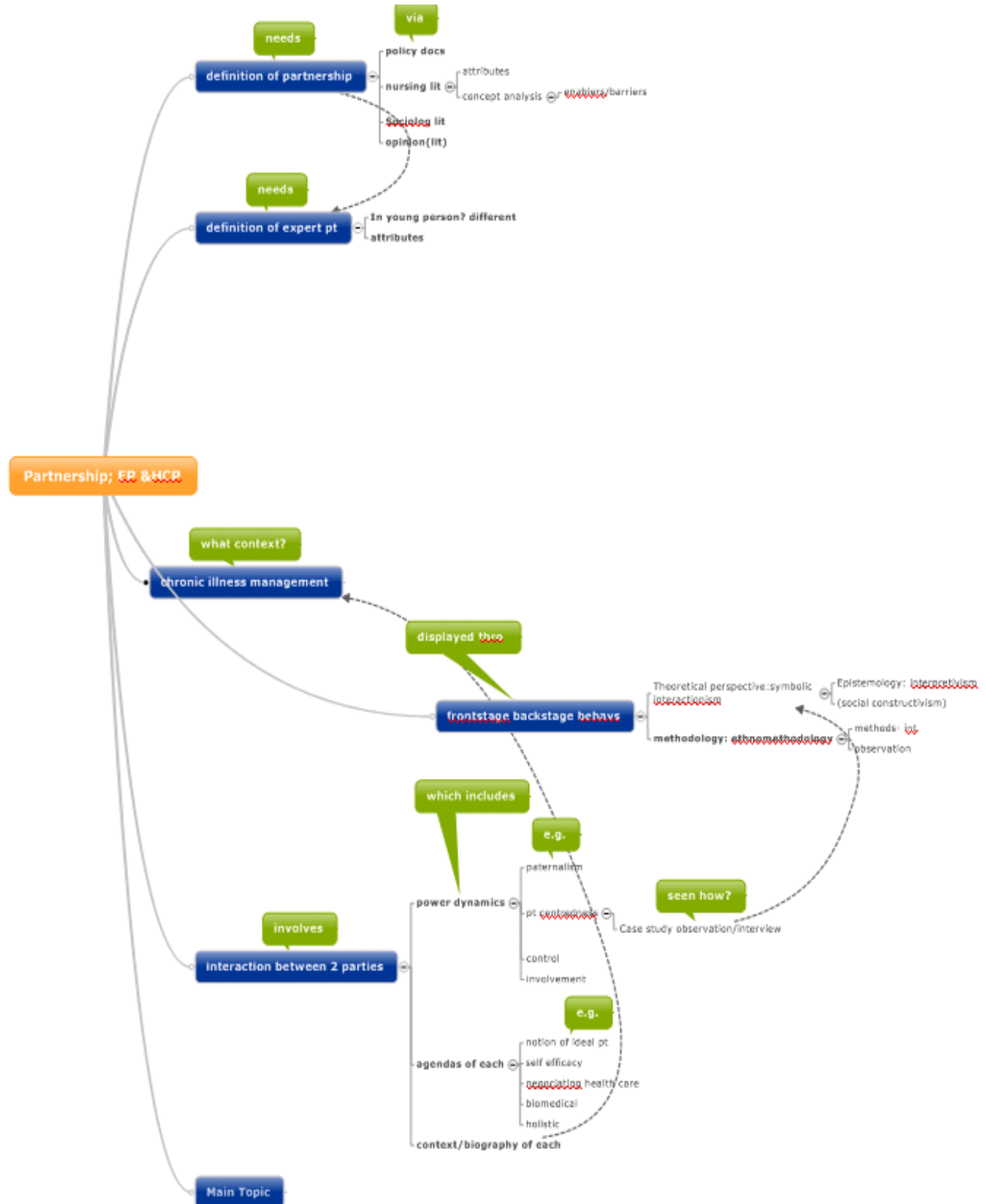
Thanks for sending me the copies of our interview and your analysis. To be quite honest I think you have everything as close to spot on as possible. The statements you have chosen and the categories you have slotted them into seem accurate and well understood.

I must admit I cringed slightly at some of the words I used when I seen them in writing..... Good "auld" Scottish for you though.

Thank you again for keeping me in the loop and please do not hesitate to contact me for any further help or involvement.

.....

## APPENDIX 19: Early mind map: partnership (Figure 3)



**Appendix 20: Table 13; Analytical and *A priori* themes**

<b><i>A priori</i> themes</b>	<b>Analytical themes</b>
Experiences of partnership (barriers/ enablers)	Building bridges to achieve adherence: "getting them to do things" Gentle surveillance
Relationships and what influences them Duration Frequency of contact Respect commitment	Professional friendships Unwritten rules of engagement Holistic knowledge of patients The apparent power of the nurses
Negotiation	Choosing your battles & meeting in the middle Playing the long game/gentle persuasion Frustration HCPs as too soft
Experiences of the clinic	Ceremonial order of the clinic Bureaucratic format Unwritten rules of engagement/cues/concerns Emotion work Rules of the frame (Goffman)
Attributes of the expert patient Experience v's expertise	Patient as navigator, vigilant, monitor, tester, planner

**Appendix 21: Table 14; Emergent and Analytical themes**

<b>Emergent themes</b>	<b>Analytical themes</b>
Nurses role in partnership	Nurse as powerful broker Nurse as covert coercer Conscious continuation of Dr/nurse game
Support as a barrier and enabler of partnership	Parental surveillance
Influences on adherence	Impact of Life event/ stage competing priorities/agendas
Constructions of illness	Revisioning normal minimisation Embeddedness (of routine/ Self-Management)
Trust	Honesty (patients) v's belief (HCPs)
HCPs as too soft	Compromising unwritten ground rules to maintain relationships
Emotion work	Giving cues, fishing, humouring, plotting
Expert patient as navigator	Circumventing unwritten ground rules to achieve personal outcomes